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Patients' and Nursing Staff
Perceptions and Experiences of
Direct Patient Care: an
ethnographic study in a
haemodialysis unit

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Abstract

Background: Direct patient care is a term being used within nursing and healthcare. The term is used to explain what the nursing and clinical support staff are doing during a rostered shift. One particular area in which patients attend regularly and require a large amount of nursing support is the haemodialysis unit. Patients attend this department usually for three to six hours, with treatment lasting from three hours to over five hours. Patients require to attend three times a week to receive long but lifesaving treatment through one form of renal replacement therapy.

Aim: This doctoral research was designed to explore the idea of ‘direct patient care’ within one specific context, where patients spend a great deal of time in a healthcare setting- the haemodialysis out-patient unit. This study aimed to explore nursing staff’s and patients’ experiences and perceptions of direct patient care in this area.

Methods: The research used an ethnographic approach, using an insider as the researcher, due to holding an existing nursing position in the area, and was conducted between December 2013 - August 2014. The research considered both registered nurses and healthcare support workers, as well as patients, as participants. Data was initially collected using participant observation; using fieldnotes, informal questioning and photographs. Observation sessions lasted between 4-6 hours covering the different days and shifts. 27 Semi-structured interviews were also used in a small purposive sample of all participant groups. This variety of methods allowed for the views and experiences of haemodialysis patients, registered nurses and clinical support workers to be gained.

Results/Findings: The analysis uncovered that direct patient care was the provision of safe, comfortable and individualised care. Direct patient Care was then identified to be delivered in two ways- actively or passively. Active care follows the more traditional understanding of time together, through engagement or interaction. Passive care identifies that staff being visible and available for patients, despite not being in close proximity or directly caring for patients, still allows a patient to be cared for, and in turn, staff feel they are caring for the patients during their time in this environment. Underpinning both of these ways of direct patient care delivery is

the individual connection between the member of staff and the patient. The connections within the haemodialysis unit are part of this ability to deliver active and passive care. The individual connection between a patient and either a registered nurse or support worker facilitates this. The familiarity of each of these groups to each other, rapport, trust and being interested allow for this individual connection.

Conclusion: Direct patient care in the haemodialysis unit can be understood using a conceptual model, where the process of delivering this direct patient care is either by active or passive care, with both allowing the provision of safe, comfort and individualised as part of direct patient care.

Lay Summary

This research was designed to gain an understanding of patients', registered nursing staff and healthcare support workers' experiences and perceptions of 'direct patient care'.

Direct patient care is a term being used within nursing and healthcare. The term has been used to define what the nursing staff are doing during a rostered shift. The aim of this ethnographic study was to understand more about what direct patient care looked like within one specific healthcare setting; the haemodialysis unit.

Haemodialysis is a treatment for people who have kidney failure and require to attend for this type of treatment usually three times a week, for three to six hours a time at an out-patient unit, mainly staffed by registered nurses and healthcare support workers.

Using an ethnographic approach involved the researcher participating in people's everyday lives. It allowed the researcher to explore what patients want and value as part of this direct patient care that they receive, their experiences of quality patient care and the interactions from both registered nursing staff and healthcare support workers within this environment. Data collection allowed the researcher to observe the patients and members of nursing staff as they undertook the day-to-day duties. Data collection was primarily through observations where the researcher wrote fieldnotes, asked informal questions and also took photographs, to show what occurred over an eight-month period. 27 semi-structured interviews were also undertaken, with a sample of both registered nursing staff and healthcare support workers, along with patients from the area.

The research has uncovered that direct patient care was delivered in two different ways in the haemodialysis unit, actively or passively. Active care involved an engagement between the staff and patient, whereas passive care was delivered by staff who were available and visible to patients. Both of these ways of delivering care provided safe, comfortable and individualised care to patients. The results improve understanding and contribute to providing high quality nursing care for this specific patient group, with this new understanding of care delivery.

Declaration

I declare that this thesis has been composed solely by myself and that it has not been submitted, in whole or in part, in any previous application for a degree.

Signed: *Alisan Wood*

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Abbreviations

APD - Automated Peritoneal Dialysis

CAPD - Continuous Ambulatory Peritoneal Dialysis

CAQDAS - Computer Assisted Qualitative Data Analysis

CASP - Critical Appraisal Skills Programme

CVVH - Continuous Veno-Venous Haemofiltration

CKD - Chronic Kidney Disease

DPC - Direct Patient Care

ERF- Established (chronic) Renal Failure

ESRF - End Stage Renal Failure

FOC - Fundamentals of Care

HD - Haemodialysis

IDWG - Interdialytic Weight Gain

NHS III - NHS Institute for Innovation and Improvement

NHS - National Health Service

NMC - Nursing and Midwifery Council

PD - Peritoneal Dialysis

PW - Productive Ward

RRT - Renal replacement therapy

RTC - Releasing Time to Care

TCAB - Transforming Care at the Bedside

PCN - Person-centred Nursing

PCP - Person-centred Practice

PCC - Person-centred Care

ICU - Intensive Care Unit

Chapter 1 Introduction

Research into health issues and healthcare has a high value to people and society. It is important to research many aspects of health so that information can be uncovered or become better understood. Knowledge gained from research can focus on patient outcomes, experiences, risk factors or disease patterns, all of which can improve care or practice within health and therefore can have a huge benefit to many people in society.

This research, work and subsequent thesis was inspired by clinical practice and involvement in implementing a programme within a particular clinical area, which left some unanswered questions for the staff, a group that includes the researcher.

This thesis explores the concept of direct patient care within one particular patient care context or environment: the out-patient haemodialysis unit. This chapter begins by outlining the background and context of the study, highlighting the background to this particular concept and this particular clinical area. It considers the research approach, and also considers other published research using the same research design and clinical setting. This chapter concludes with presenting the overall structure of the thesis.

1.1 Background

The Scottish Government have produced the *Healthcare Quality Strategy* (Scottish Government 2010a). The Quality Strategy follows on from their previous document *Better Health, Better Care* (Scottish Government 2007) and continues with the aim of delivering a patient-centred health service in NHS Scotland.

This document explains how NHS Scotland aims and plans to deliver ‘millions of individual care encounters that are consistently person-centred, clinically effective and safe, for every person, all the time’ (Scottish Government 2010a p1). Person-centred care is where treatment and care takes into account a person’s needs and preferences and is viewed as the cornerstone of modern healthcare (Pelzang 2010).

Within this Quality Strategy, it is acknowledged that what patients value in healthcare as important priorities are key within the development of NHS Scotland.

The quality strategy also suggests the importance of time spent with patients is thought to be related to an improved quality of care.

Within the NHS and healthcare provision there has been a shift in focus towards efficiency and effectiveness of care and services. One such programme which seeks to deliver this in Scotland is what began the development of this PhD research. It is also one of the interventions that the Scottish Government believes will allow staff to deliver safe and effective patient-centred care. The Releasing Time to Care (RTC) programme improves effectiveness and efficiency and strives to improve the direct care time that staff can provide to patients. The Scottish Government have prioritised the implementation of this programme across acute and community teams in the Healthcare Quality Strategy (Scottish Government 2010a, 2010b).

One aspect of the RTC programme involves trying to increase the time spent directly with the patient when they are in a healthcare setting or environment. Direct patient care, or DPC, is measured in minutes, and through the direct observation of staff whilst carrying out their usual clinical work, a value is given to how much time is spent directly with patients. The higher the value, the better, as this high level of time with patients is considered as one way to improve patient experience.

1.2 Context of this study

To set the scene for this research, several different elements are considered, to provide an understanding of this particular environment under study, as well as the RTC programme and the concept of DPC, which has a focus in this research.

The research site used in this research is a renal haemodialysis unit. Haemodialysis is an aspect of renal medicine and considered a specialised field, which is reflected in the complex care these patients require. Renal nursing is unique and different to other types of nursing (Morehouse et al 2001). With increasing numbers of patients who have kidney disease (Thomas 2004), the speciality of renal nursing will continue to develop. Patients who have kidney injuries or diseases that can lead to kidney or renal failure may then require specialised treatment for their condition to keep them alive (Hagren et al 2001, Bevan 2000).

When the filtrate formation reduces or stops entirely in renal failure, the metabolic waste products build up in the blood and disrupt the body's normal processes.

Whilst the ways to treat the build-up of these waste products is different in an acute kidney injury, as the hope is the kidney will recover, in end-stage renal/kidney failure (ESRF/ESKF) or established renal failure (ERF), long-term renal replacement therapy (RRT) is needed. Some patients do not go onto RRT treatment and are managed using supportive or conservative care (Noble et al 2008).

These waste products require to be removed by the use of RRT; these are kidney transplantation, haemodialysis (HD) or peritoneal dialysis (PD) (Thomas 2014).

The number of people in Scotland who start RRT is continuing to increase. The life expectancy for patients who receive RRT is shorter than the general population, despite improving survival rates for patients starting RRT (NHS National Services Scotland 2015).

On the 31st December 2014, using the Scottish Renal Registry data set, in Scotland 4761 patients were receiving some form of RRT, either being treated with haemodialysis, both forms of peritoneal dialysis (PD) or have a functioning kidney transplant (see Table 1) (NHS National Services Scotland 2015).

Table 1: Prevalence Data taken from SRR data for 31st December 2014

Mode of RRT	Number	Percentage
Kidney Transplant	2677	56%
Hospital HD	1814	38%
Home HD	59	1%
Continuous Ambulatory Peritoneal Dialysis (CAPD)	70	1%
Automated Peritoneal Dialysis (APD)	141	3%
Total ERF patients receiving RRT	4761	100%

<http://www.srr.scot.nhs.uk/Publications/docs/Scottish-Renal-Registry-Report-2014-web.pdf?3>

The most common treatment for the ‘usually’ irreversible disease of ERF is a renal or kidney transplant, with the patient numbers for haemodialysis (HD) as a treatment option being only slightly fewer than this.

The provision of RRT in the form of haemodialysis has occurred since the 1950’s, allowing people with little or no kidney function to continue to live. The first patient was dialysed for established renal failure (ERF) in Scotland in 1960 (NHS National Services Scotland 2015). People who require haemodialysis must face their own mortality on a daily basis (Aswanden 2003) as non-attendance can result in feeling unwell and lead to death.

For patients who follow the HD treatment route, the regular connection to a haemodialysis machine to substitute some of the normal kidney function is a necessity. These patients normally attend 3 times a week, with treatment lasting between 4 to 5 hours each time. This treatment is where a machine replicates the normal kidney processes in which all the excess fluid and waste products are removed from the blood (Thomas 2014). An artificial kidney cleans the blood by diffusion. Haemodialysis allows for the maintenance of fluid and electrolyte balance without having any kidney function (Richardson 2006). This is usually done in a renal or haemodialysis unit. Despite RRT improving, haemodialysis continues to be a difficult treatment and continues to have an effect and consequences on patients and carers (Noble 2012).

1.2.1 Renal Units

Haemodialysis treatment is usually provided in a renal unit, with only 3% of HD patients receiving their treatment at home in Scotland (NHS National Services Scotland 2015).

A main renal unit provides a continuum of care for adult patients suffering from renal disease. (DOH 2013a). A main unit is usually part of a large hospital, which has a renal ward and renal high dependency areas within this hospital on site. The patients who attend the main unit can attend this specialised unit for different reasons (see Figure 1). This contrasts with a satellite renal unit, where the majority of haemodialysis patients are considered to be stable and, although requiring long-term

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care in the form of haemodialysis treatment, they do not need the highly-specialised treatment that can only be provided in a main renal centre (DOH 2013b).

Patients attending a main renal unit may be:

- of any adult age;
- ambulant, in a wheelchair, or arrive on a stretcher/trolley;
- physically disabled and/or sensorily impaired;
- acutely or chronically ill through renal disease alone or through renal disease in combination with other renal-related or non-renal-related pathologies and co-morbidities;
- low-dependency maintenance haemodialysis patients for whom the main renal unit is their most convenient dialysis facility;
- transplant recipients who attend the unit as inpatients and out-patients after surgery.

Figure 1: Patients who may attend a main renal unit (DOH 2013a p2)

Mendelssohn and Benaroia (2008) have described out-patient haemodialysis units as factories. This account illustrates the focus on the tasks rather than the patients in haemodialysis settings and the difficulty in spending time caring for patients in this setting. This indicates the need for an increase in caring practices from nursing staff towards their patients to ensure that patient-centred care is delivered.

Renal and haemodialysis units are very reliant on equipment with sounds and visual indicators to show any issues to the nurses. The sounds and the environment in these areas are very unique, with many different alarms at varying intensities and frequencies (James 2008).

Haemodialysis nursing is characterised by the frequent and intense contact with patients in a complex and technical environment. Haemodialysis treatment, when conducted in hospital rather than in a patient's home, usually requires significant nursing support in a main renal unit, where patients are attended to by nursing staff, and therefore spend a significant amount of time in the unit with this staff group.

Within renal units there are different groups of nursing staff who have varying roles. Considered in this research are registered nurses and healthcare support workers. Registered nurses are registered with the Nursing and Midwifery Council (NMC). The other group of nursing staff located in this renal unit are healthcare support

workers or clinical support workers. This is an employee who has a direct clinical role, but is under supervision, and has access to patients and members of the public. Both of these roles have direct contact and provide care to haemodialysis patients when they attend for their treatment.

Haemodialysis care is delivered in different ways in different countries across the world. In Australia, assistants were introduced into haemodialysis units (Chow and Miguel 2010) and in the United States of America registered nurses, licensed nurses and technicians can work and perform haemodialysis in specialised renal unit centres (Wilkinson et al 2014, Garbin and Chmielewski 2013).

The workforce within the UK and NHS is still changing, and the consideration of both staff groups in this research is important, as they currently both have a role which involves patient contact and care provision.

1.2.2 What is Releasing Time to Care?

In 2007, the NHS Institute for Innovation and Improvement (NHS IHI) launched the Productive Ward (PW) as part of a wider original productive series (NHS IHI 2011). The same programme was then launched in NHS Scotland, under a different title of Releasing Time to Care (RTC) in 2008, with the conclusion of the national implementation programme in October 2013 (Healthcare Improvement Scotland and NHS Education for Scotland 2013, Scottish Government 2010b, NHS Scotland 2010).

The original PW programme, and therefore the RTC programme, is based on LEAN methodology. LEAN is an improvement approach which has its origins with the Toyota manufacturing process, which reduces activities which do not add value (Brandao de Souza 2009). LEAN principles eliminate waste, improve flow and positively change inefficient processes and have become increasingly modified and implemented for use within healthcare (D'Andreamatteo et al 2015). The PW programme has been implemented in other countries as well as Scotland, including New Zealand and Canada (Healthcare Improvement Scotland 2012, NHS Scotland 2011).

The PW and RTC programmes are specifically focused on the improvement of the nursing environment and their processes are to increase direct patient care (Robert 2011, Glenn et al 2011). The PW and RTC programmes have also allowed staff to target issues which they feel require to be focused upon and resolved e.g. organising equipment (Davis and Adams 2012). These productive programmes aim to improve staff and patient experience, improve patient safety and increase direct patient care time (Foster et al 2009). Nurses agree that the programmes support what they want to do with their own wards and workplaces (Robert et al 2011).

The programmes focus on increasing the time spent on direct patient care time by nurses (Lipley 2009). Staff felt that patient care suffers, due to the lack of time that nurses spend with the patients as they are too busy (Nolan 2007).

The PW and RTC use 11 different modules for the ward leader and staff to work through, one at a time (see Figure 2: Productive Ward House). These modules allow the leader to focus on one specific aspect of the programme at a time and to manage the changes for the team.



Figure 2: Productive Ward House

http://www.institute.nhs.uk/quality_and_value/productive_ward/the_productive_ward_house.html

The three core modules are at the bottom of the house and they need to be implemented first before the other modules above them. These are; knowing how we are doing, well organised ward, and patient status at a glance. These modules prompt staff to think about how they spend their time during a shift, and by considering these modules, the workplace can be transformed to make it and the staff more efficient (Allsop et al 2009, Foster et al 2009).

From the implementation of these programmes across different areas of the NHS in the UK, improvements in direct patient care time have been identified.

Improvements in direct patient care have varied from across the NHS, with increases reported as 28% in an elective and trauma orthopaedic unit (Smith and Rudd 2010), 12-15% across a whole NHS trust in England (Foster et al 2009) and also small increases from 38% to 44% across one large university teaching hospital (Bloodworth 2009). In a dementia unit, the direct patient care percentage was not detailed, but the handover time was reported as reducing by 50%, and medication rounds have been reduced from 34% to 23% of nurses' daily activities since the implementation of RTC (Armitage and Higham 2011).

It has been suggested that the PW and RTC programmes, in addition to increasing direct patient care, provide other benefits to patients and nurses, despite the programme being simple and straightforward to implement (Wilson 2009). Wilson (2009) has commented on units which have successfully implemented the RTC programme, stating that they have found benefits in team working and that the ward atmospheres appear calmer. An evaluation on the program in Belgium found nurses working on wards which had implemented PW had shown an improvement in job satisfaction levels and a reduction in intentions to leave the profession (Van Bogaert et al 2014). This evidence suggests that the programme could potentially have a benefit on staff retention. Bradley and Griffin (2015) found the programme empowered staff in the particular area who were implementing the project, even if they were not hugely involved in the implementation.

Armitage and Higham (2011) have suggested that staff morale improved when they felt involved and were listened too. This is a key part of the RTC programme. The use of strategies like a thank you tree, which displayed cards to the staff from

patients and the sharing of information about themselves with other members of staff helped increase participation in small tasks. This motivated the staff to implement changes and engaged with the larger tasks (Armitage and Higham 2011).

From using the modules to explore patient safety in wards, areas have been found to be specifically problematic and improvements have been made to limit the effects of these problems. One area was identified that all patient falls happened on a Tuesday, which was the main theatre day, so staff were distracted with the collecting and taking patients to theatre. Staffing was then looked at to make sure that adequate staffing levels were in place on the ward to prevent this (Wilson 2009). Medication rounds also have been documented to be shorter and with fewer interruptions occurring to nursing staff when undertaking the task. This has resulted in safety improvements when performing a medication round (Wilson 2009).

Although PW and RTC appears to be well supported by the Government and NHS Managers (Morrow et al 2012), some clinical staff on the ground have been resistant to changes in practice made from the implementation of the programme. Armitage and Higham (2011) and Blakemore (2009) have both commented on resistance to change from staff and their reluctance or unwillingness to become involved. Even the sabotaging of RTC activities has been documented, with the programme boards being sabotaged, information being wiped away and clean and tidied cupboards becoming messed up (Armitage and Higham 2011). This is echoed by the author's own anecdotal evidence and experience, with many staff reluctant to become involved in RTC activities. Staff also made comments of feeling insulted on being told that they need to change their practice, and as if it is felt that they do not already 'care' as part of their nursing practice.

The leadership of a project like this is hugely important (Armitage and Higham 2011) (Morrow et al 2014). Both the PW and RTC programmes have a toolkit for the ward leader to help them facilitate the changes in their workplace. The ward leader must believe in the value of the project and be actively involved in supporting change. The whole team must be involved, but the leader must direct the project (Armitage and Higham 2011). By involving all members of the team from domestics, staff nurses, support workers to medical staff, different perspectives will

be gained and hopefully this involvement will help keep staff invested and motivated in the project. Smith and Rudd (2010) have suggested that change is not only about cost saving, it is about improving the quality of care and patient experience.

There are various applications of parts of LEAN principles and other programmes similar to RTC implemented across the world, all aiming to increase efficiency in healthcare settings e.g. Transforming Care at the bedside (TCAB) (Brackett et al 2013) and Nursing Works (O'Neill et al 2011).

By implementing the PW or RTC programmes, and therefore increasing efficiency, changing practice and the work environment, it is hoped that time can be released for nurses to spend more time with patients, and therefore be able to provide more direct patient care (DPC) (Lennard 2012, Smith and Rudd 2010, Lipley 2009, Wilson 2009). This aim of the RTC programme will be indirectly explored through this research, as it will gain nursing staff and patients' perspectives on what DPC is within the haemodialysis out-patient context.

There are some limitations with the implementation of LEAN methodology and other similar programmes. A literature review which evaluated research on a different programme, TCAB, Brackett et al (2013) was unable to conclude that the implementation of these practices directly affects the care provided or the time spent at the bedside by staff. Whilst implementation on varying scales was able to improve processes and make things more efficient, it does not directly correlate to increased time with patients.

Despite these reported limitations, programmes have been successfully implemented and have reported to provide benefits. The RTC programme specifically has been evidenced to have a positive impact for staff, as well as changing and improving routines and ward environments (Armitage and Higham 2011, Smith and Rudd 2010, Bloodworth 2009, Wilson 2009).

Through implementation of programmes such as this, there would aim to be an increase in time for direct patient care, potentially allowing the delivery of a more

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patient-centred service as outlined by NHS Scotland (Healthcare Improvement
Scotland and NHS Education for Scotland 2013, NHS Scotland 2010).

1.2.3 Direct Patient Care

The crucial element of RTC and PW's success is the collection and measurement of how staff spend their time, and any changes or improvements in the way their time is spent as the programme is implemented.

Successful implementation of the PW/RTC programme have shown improvements in direct patient care time (Wright and McSherry 2013). In both the PW series and the Scottish renamed programme, RTC, direct patient care (DPC) is termed 'time at patient bed or near patient' and this requires to be measured. Appendix 1 further details direct care time as a measure taken from the RTC information.

DPC is measured as part of the programme through an activity follow or observational audit. An activity follow is where someone stands and observes a member of staff and what they are doing every minute of their shift and records this on a chart. Every minute, whatever the activity or task the member of staff is doing, must be marked down and accounted for. This could include patient-related activities, answering phones, walking around, hand washing or a discussion with other staff members.

The activity follow shows how much time is spent directly with patients and on direct patient care tasks. It can also identify when staff are doing wasteful activities e.g. walking, looking for items or interruptions and the observer then logs their activity every minute, as either as direct care activity, enabling care activity or another type of activity such as motion or non-patient related discussion.

The activity follow descriptors suggests that DPC is time spent with a patient or several patients at once, including ward rounds, handovers and drug administration done in the presence of a patient. It highlights the tasks being carried out by the member of staff being observed during their time at work or rostered shift (See Appendix 2 for examples of the specific different direct patient care activities from

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different settings and Appendix 3 for descriptors of the ways in which the time spent is categorised within an activity follow).

The activity follow can also identify any improvements or changes in direct patient care and could potentially allow better healthcare delivery in the clinical setting.

The RTC programme activity follow was further adapted to identify another aspect to nursing work as 'enabling care'. This is for all patient related activities which do not occur in the presence of the patient and were now seen as ways to add value, such as changing gloves or handwashing, compared to the staff being in motion between tasks or doing cleaning which were termed as a no value-added activities.

This increased time is then intended to provide nurses and other health care professionals to spend more time with patients through making the entire setting more efficient and removing wasteful processes which could improve safety and patient care. Wards, community hospitals, mental health wards and operating theatres can all implement the releasing time to care programme specific to their work area. Key to the success of the programme is the involvement of frontline staff to implement the changes (Robert 2011).

One paper describes the implementation of the RTC programme in Scotland in different mental health settings. Lamont (2012), when implementing an older person setting, has illustrated an improvement in direct care time from 34% to 60%. Following further implementation in an acute in-patient environment, direct care time has increased from 48% to 65%. However, this does not provide patient or staff experiences of this direct care and there is no guarantee that this care is well-received or of high quality nurse/patient interactions.

Anecdotally, settings like intensive care units (ICU) where staff do not leave the patient's bedside have a very high proportion of direct patient care, however this time with the patient does not necessarily equate to the provision of high quality care.

A definition of what direct patient care is, or is not, forms part of the research aims of this research project. The RTC programme regards direct patient care as when a nurse or support worker is close to a patient or delivering direct care.

Within the final report for RTC (Healthcare Improvement Scotland and NHS Education for Scotland 2013), direct patient care time has shown to have been improved through the implementation of the programme across different settings although the term DPC was not explained within the report.

In one evaluation of PW, some staff felt the programme had released time for more time with patients, while others felt that this released time was then used for other activities (Wright and McSherry 2014).

To further provide a background to the research conducted as part of this PhD, the term direct patient care in the literature is now considered. The topic of this research has a focus on the concept of direct patient care, and whilst this has some direct correlation to the RTC programme, other additional literature also exists which considers the term and associated nursing activities.

Considering what nurses do during their rostered shift when at work is a factor which has had some attention in nursing research and literature. In 1953, The Nuffield Provincial Hospital Trust published a report of the work of nurses in hospital wards as a result of an extensive job analysis. They divided the nurses' time spent as either 'nursing', 'domestic' or 'ward organisation', and within nursing there was a distinction drawn between time spent doing either basic nursing or technical nursing. This work examined 26 wards in 12 different hospitals, observing for a complete week to establish the weekly routine. The authors acknowledged that the list of tasks and duties does not fully convey the atmosphere of a ward or environment, highlighting the potential issues when classing the work of nurses as activity-based (Nuffield 1953 p25).

Some quantitative research has been undertaken on direct and indirect patient care and nursing activities. Different studies using a variety of settings have described and classified nursing activities differently. Despite direct care being classified differently, it is understood that it is an important part of nursing (McCloskey et al 1996), and that it can be a variety of tasks and skills: maintaining comfort, assisting with movements, bathing, toileting, nutrition, medication administration and technical skills.

Hendrickson et al (1990) classified nurses' activities into four different categories depending on what the nurse was doing. These were firstly being with patient, indirect and clinical, indirect and non-clinical and the final category was miscellaneous and non-clinical. The activity category of 'with patient' was all the nurse and patient time together. This contrasts with a study within a nursing home context which classified direct care activities as all nursing activities performed in the presence of a patient/resident or a relative, but did not include medication and communications (Munyisia et al 2011). Jinks and Hope (2000) classified nurses' activities in two ways; either as direct or indirect patient activities, and also as separate nursing care and environment, organisation and management, therapeutic interventions, diagnostic and monitoring and education and coaching. The direct patient care was defined as being in direct contact with patients on any task.

Chaboyer et al (2008) further defined in their study that direct care was patient care activities in close proximity to patient, and indirect care was where patient care activities were undertaken away from the patients. However, this was not further explained or quantified as to what distance was considered as being away from the patients. The indirect tasks included handovers and team meetings, progress notes, communication, room set up, cleaning and medication preparation.

In ICU settings, some have considered patient assessment as a non-direct care activity (Kaya et al 2011, Harrison and Nixon 2002), although others consider this to be direct care, due to the patient being present as part of the assessment (Munyisia et al 2011, Jinks and Hope 2000, Hendrickson et al 1990) as it is difficult to assess a patient if you are not in direct contact with them. This would therefore conflict with those who would class this as direct care as the patient is present.

Some research on nurse and patient interactions with psychiatric inpatient services have highlighted that not all patients spend time with nurses, and if they do it is not always providing therapeutic intervention (Sharac et al 2010, Whittington and McLaughlin 2000). Whittington and McLaughlin (2000) found that social conversation and patient contact featured within these interactions. These interactions would be classed as direct care in terms of the RTC programme and activity follow.

In all of these studies that regard being in close proximity to the patient to be important, none had explored how patients felt about it, or what the staff perceptions were of the direct care they were providing. The studies were all quantitative in design, and an understanding of the patients' views of this direct patient care time or activities was not sought. This highlights the lack of qualitative research in this aspect of nursing practice and that there is no research on this topic within haemodialysis care environments.

Teale (2007) anecdotally describes the 'invisible barrier between the nursing station and the patient areas' (Teale 2007 p97) that she has witnessed in practice, with nurses only crossing this line to carry out specific tasks and then returning to the desk. She describes the nursing staff having no interaction or communication with the patient and therefore, whilst delivering direct patient care, the lack of interaction may not be regarded as high quality care.

The consideration of nurses' interactions with patients has been considered in previous work. Crotty (1985) explored interactions between nurses and patients in an in-patient area, considering the verbal communication which occurred between these two parties. Crotty suggests that

'carrying out nursing care for the patient does not ensure that interaction takes place' (Crotty 1985 p134).

This statement highlights the problems with considering direct patient care as being near a patient, as this care may not necessarily include talking to a patient.

Milne and McWilliam (1996) highlighted in work examining nursing as a resource that nursing was experienced as 'caring time'. This caring time was experienced as either being with a patient or doing for/to a patient. Nurses would be able to be with patients through connecting with patients in this being together.

Kitson (1986) argued good quality care is not only undertaking activities but it goes further to include what the nurse actually does to and with the patient as well as how it is done. This highlights the necessity for this research to be conducted, to

understand what care is in this setting, as well as the activities which can constitute this.

1.3 Research Aim and Questions

The aim of the study was:

To gain an understanding of patients' and staff perceptions and experiences of 'direct patient care' within one large in-hospital haemodialysis unit.

The specific research questions were:

- To establish what the patients want and value as 'direct patient care' in the haemodialysis unit
- To explore patient perceptions and experiences of 'direct patient care' and interactions
- To establish what haemodialysis registered nursing staff view as direct caring activities for haemodialysis patients
- To establish what haemodialysis clinical support workers view as direct caring activities for haemodialysis patients

1.4 Study approaches

The research uses an insider 'focused' ethnography to explore these research aims and objectives. Using ethnography as the research design for healthcare research is valuable, due to the unique position through the immersion of the researcher in the setting. This position allows the researcher to explore the setting, behaviours and culture and explore the life world of the participants. It allows for the capture of data through this presence of a researcher in the setting and this is why researchers choose to use ethnography as a methodology for research particularly in healthcare (Roper and Shapira 2000).

Using qualitative research methods for use in renal focused research has been considered as having potential to advance renal medicine (Bristowe et al 2015).

Using multi-method data collection techniques; observations, fieldnotes, photographs and semi-structured interviews, with all identified participant groups allowed for the exploration of the research question and objectives.

1.4.1 Previous Renal Ethnographic Research

Whilst the use of ethnography will be explained and discussed further within this thesis (Chapter 4), it is considered important to review the literature that has previously utilised this research design in a renal or haemodialysis setting.

Ethnographic research is naturalistic, and is influenced or mediated by the culture or setting in which the research occurs (Hammersley and Atkinson 2007, Roper and Shapira 2000). As ethnography data is led from the field, the studies have all generated different data due to the observations and research questions, so an ethnography in a similar area will provide data relevant to the research question, although it is carried out in a similar setting.

One ethnographic study which was conducted in a haemodialysis unit aimed to illustrate how understanding the unit culture would facilitate more patient-centred care (Ashwanden 2003, Ashwanden 2002). The study collected information over a two-year period and examined the culture and partnerships between the nurse and patients in two different haemodialysis units in the UK. This ethnographic study highlighted the importance of the nurse-patient relationship and the idea of partnership, but did not focus or identify the direct care or caring practices which occurred in the units.

Tranter et al (2009) used ethnography to explore how nursing care was conducted in a small haemodialysis unit in Australia. They suggest the machine and provision of treatment is dominant, and that not much else is seen. They have suggested that the culture of the unit has evolved, where nurses are unable or unwilling to provide patient centred care, which addresses the total needs of the patient. They also identified that the nurse-doctor relationship was a barrier to patient centred care. The nurses in this study were asked if they provided technical or patient centred care, but the research did not explore if the technical care could be viewed as direct care due to the potential presence of the patient. This ethnographic study also considered what it was like to be a haemodialysis patient; the physical, social and psychological symptoms and limitations. The study interviewed 12 patients, but the research did not identify what the patients wanted or felt about the direct care they received. This

ethnography also was conducted by a clinical nurse consultant, so there are also potential issues with the researcher being the senior/lead nurse in the area who conducted the observations and what their impact was on the staff who were being observed. The study only included registered nurses however it did appear that support workers were part of the staff group in this unit. The population size was small; this was due to the small size of the haemodialysis unit. 12 patients and 10 nurses were interviewed, but different care issues may arise from conducting a study within a larger dialysis unit with larger populations of staff and patients.

Another ethnography conducted had its main focus on nurses' perceptions of quality nursing care and how aspects of power influences the quality of that care, and did not consider patients and their perceptions (Bennett 2011, Bennett 2010, Bennett 2009). The unit under study was described as a satellite unit in Australia and as having no daily medical support. A critical ethnography was conducted over a 12-month period throughout 2005. The methods included non-participant observation, interviews, document analysis, reflective fieldnotes and participant feedback showing some strength to the work with multiple methods and reflexive practice. The haemodialysis nurses viewed technical knowledge, technical skills and personal respect as characteristics of quality care, whereas long term blood pressure control and arranging transport were not seen as priorities for quality care. The person receiving treatment, the management, nurses and the environment were all seen as factors determining this provision of quality dialysis nursing care. This study, whilst considering the registered nurses, neglected the haemodialysis patients' perceptions. This vital viewpoint has not been included in the research design and the research conducted here has been able to include the patient participants' views and therefore limits the results of this research.

A small study using an ethnographic approach explored indigenous Australian people who were undergoing haemodialysis and peritoneal dialysis (Burnette and Kickett 2009). The study did not use observations as part of their data collection, but they identified, through six participant interviews, that haemodialysis patients felt vulnerable. The study identified that their lived experiences and the relationships, or lack thereof, with nurses meant that the patients felt misunderstood, and it was

suggested there was poor communication between staff and patients. This study did not involve staff as part of the data collection and by neglecting this group within the study, it does not allow for the full exploration of this communication.

Blogg and Hyde (2008) used ethnographic analysis on fieldnotes and semi-structured interviews with five couples in their own home to understand spouse experiences of home haemodialysis. Observations lasted three hours, and included an interview with the spouse. The use of ethnographic methods allowed the understanding of this particular group, but longer observations may have been impractical due to the treatment occurring in the participant's own home.

An ethnographic approach was also used by Waters (2008) to explore the experiences of children and young people in a children's renal unit. This work, over 16 months, used interviews and observations across in-patient and out-patient renal areas, along with children's drawings, to understand how they conceptualized their experience of having a chronic renal disease.

A renal or haemodialysis setting is a suitable environment to explore the use of ethnography, as the patients are required to present for treatment on a regular basis, allowing continued and regular access to patients making the population easier to access than other patient groups.

These above studies, despite using a similar research approach and considering hemodialysis and renal patients and the related settings, do not directly consider the question posed in this research, and demonstrate there has not been any similar research conducted on this topic in this area.

1.5 Structure of the thesis

Following this introduction, in Chapter 2 a review of relevant literature is provided to identify aspects of patient care in haemodialysis units and related renal care settings. It also allows for the exploration of current practices and current research in the haemodialysis area involving patients and staff and the care that is provided in this setting.

Chapter 3 will explore theories and concepts of care and caring in nursing practice. The construct of caring is to be explored in order to analyse the processes and experiences of direct patient care.

Chapter 4 considers the research design and methods used in this research. The ethnographic approach and rationale for an ethnographic research design is detailed, the ontological and epistemological stance provided and details of the research process, analysis and ethical challenges explored. The chapter is then concluded presenting reflexivity, how this was used and the issues with the researcher being an insider within this particular area. Excerpts from the researcher's field diary and fieldnotes are used to illustrate particular aspects in this section.

In chapter 5 and 6 the findings of this research are presented. Chapter 5 considers the findings related to the context of the haemodialysis unit. Chapter 6 presents the findings, which relate to the previously indicated research aim and questions, and proposes a conceptual model to understand the key findings and how they relate to each other.

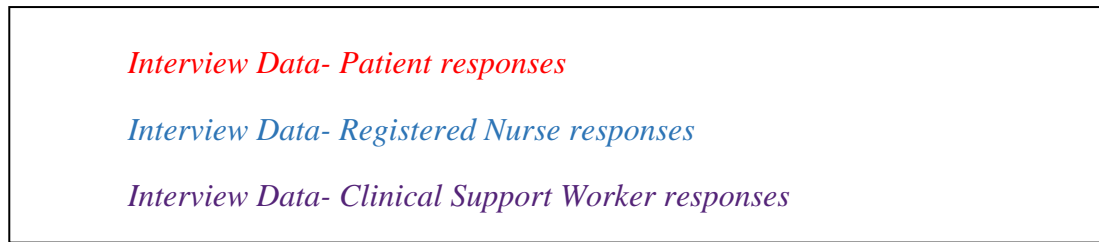
The discussion within chapter 7 covers the key themes identified within this research, considering the reconceptualisation of direct patient care in this context. Key theoretical frameworks are introduced and discussed in relation to the findings within this research.

Finally, in chapter 8, this thesis is drawn to a conclusion, discussing the implications that arise from this research and potential for further research following this PhD.

1.5.1 The presentation of raw data in the thesis

Data is presented in this thesis, not just in the two findings chapters, but also within the methodology chapters as part of the researcher's understanding of their position within the field and the data collected.

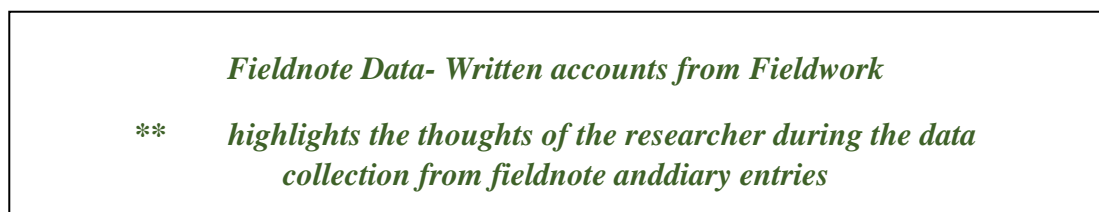
All data presented throughout this thesis uses a key to identify the way the data was collected. The key to data collected via the semi-structured interviews is detailed in Figure 3, where the participant's particular group is highlighted through the use of different colours and indented within the main text.



<i>Interview Data- Patient responses</i>
<i>Interview Data- Registered Nurse responses</i>
<i>Interview Data- Clinical Support Worker responses</i>

Figure 3: Interview Data Key

The fieldnote data is also presented in a different colour and held within a box to distinctly show the data from the researcher's fieldnotes/field diary. This data was collected through the observations and informal questions.



<i>Fieldnote Data- Written accounts from Fieldwork</i>
<i>** highlights the thoughts of the researcher during the data collection from fieldnote and diary entries</i>

Figure 4: Fieldnote Data Key

Chapter 2 Literature Review

2.1 Introduction

This chapter provides the academic background for the research study conducted as part of this thesis, focusing on direct patient care within a haemodialysis unit. The purpose of this literature review was to examine a wide variety of literature on nursing, patient care and experiences related to haemodialysis and chronic renal failure, in order to contextualise and explore the concept of direct patient care.

This literature review was conducted in order to identify and to integrate available studies and relevant literature regarding aspects of nursing and patient care in haemodialysis units and related renal care settings. From this significant systematic scoping of the literature, upon review, some similar themes regarding patient care in the dialysis setting were highlighted and are now presented. A variety of qualitative and quantitative methods were used in the identified literature, including some systematic reviews and some relevant informative literature was identified from the literature search.

During this literature review, several broad topics emerged and were used to guide the structure of this chapter and literature review. These broad headings are presented and each will be considered in turn during the literature review:

- Haemodialysis technology and treatment,
- Haemodialysis nursing care,
- Relationships between the nurse and patient in haemodialysis,
- Patient care within haemodialysis,
- Patients and their problems,
- Staff in the haemodialysis area

These topics are derived from the literature and different elements are drawn together under suitable headings, in order to create a logical structure, not only to set the context of the study, but also to present the appraisal of current literature and research in the relevant areas. The literature considers aspects of patient and nursing care for this particular group of patients and elements within the literature which are important to consider prior to conducting the research and demonstrate the clear knowledge gap in this area.

Finally, by way of conclusion, the relevance of the literature and the range of sources explored are indicated and the utility of the material in providing context for this research study is discussed.

2.1.1 Search Strategy

Literature for this chapter and review was found through a variety of means during this work. Numerous search strategies were conducted during the time of this PhD, due to the nature of this work and the time taken. This allowed for literature to be rechecked and more recent literature to be reviewed and included in this literature review.

Initially a systematic computer-based literature search was carried out using numerous databases in English. The main two databases used were ASSIA and CINAHL, due to these being the key databases for social sciences. Search strategies are presented in detail for these databases in Appendix 22. Other databases were also used and presented in Table 2.

Table 2: Databases and Search Engines Used in Search Strategy

CINAHL	Medline
ASSIA	Google Scholar
Blackwell Science Direct	British Nursing Index
DiscoverED (University of Edinburgh Library Database)	EBSCO

Search terms included combinations of key words;

- Nurs*
- haemodialysis/hemodialysis,
- renal,
- patient care,
- nursing care,
- car*
- experience
- end-stage kidney/renal disease/failure,
- established renal failure,
- chronic renal disease/failure,
- chronic kidney disease/failure

These terms were used in various combinations to identify important research articles from 1995 to date. Literature was also required to be in English, so some literature was discounted accordingly. A final flowchart for the entire literature search is detailed in Figure 5 to show the full scope of the literature search.

The search strategy was complex, as a wide variety of literature was identified through different means during the PhD process. Database searching was supplemented by references list-checking and further database searches to ensure relevant and eligible papers were not missed. Literature was rechecked and subsequent hand searching was conducted once data analysis was complete, to further update the literature review.

Papers were considered for inclusion despite being more informative pieces or lacking in original data if they were considered appropriate to the search strategy, research aim and research question. Literature was discarded that did not focus on haemodialysis treatment in an outpatient context. Some literature was identified through the search on continuous veno-venous hemofiltration (CVVH), critical care settings and also on paediatric renal care. These were discounted, as they were not relevant to this research question. Literature was identified which focused on renal failure or haemodialysis, but had a focus on either pre-dialysis or home settings. Literature was also found which focussed on transplantation as part of the search. These sources were included, because of its direct relevance to haemodialysis, and the research evidence supporting this.

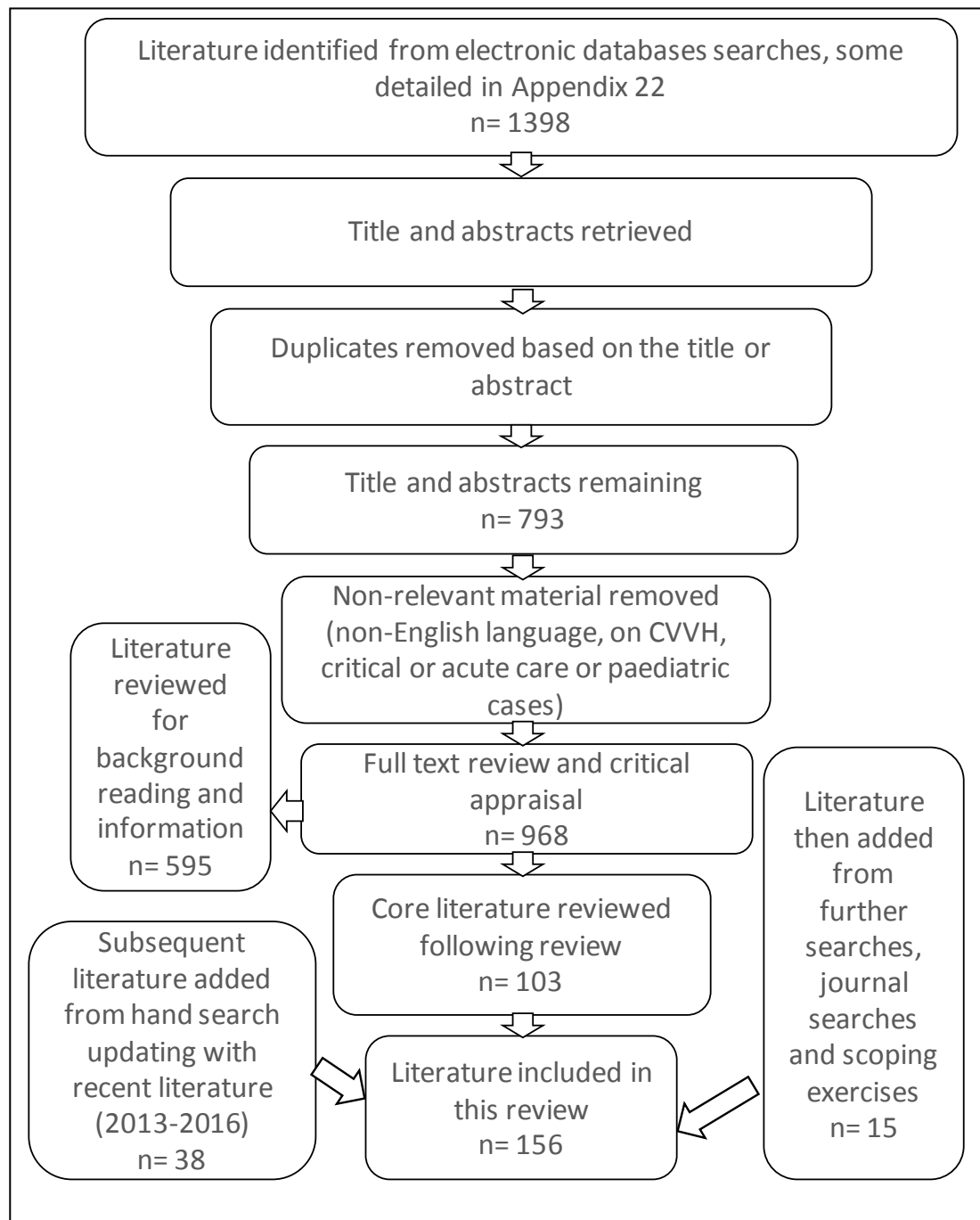


Figure 5: Final Search Strategy for Inclusion of Literature in Literature review

2.1.2 Appraisal Process of Identified Literature

The literature included in this review was considered and critically appraised prior to inclusion in the review if the literature was presenting empirical research.

Critical Appraisal Skills Programme (CASP) criteria (<http://www.casp-uk.net/appraising-the-evidence>) were used as a framework for reviewing the research

papers identified in the search strategy and therefore for their inclusion in the review. The evidence was reviewed and judgements were made on the reliability, validity, trustworthiness and relevance of the research identified.

2.2 Haemodialysis Technology and Treatment

2.2.1 Technology and Environment

The haemodialysis unit is a place where lives are saved. Patients want to feel welcome to the area (Kaba et al 2007). The haemodialysis unit is usually a loud and highly technical environment (James 2008) and will undoubtedly have an impact on the patients' experience. Likewise, nurses also have identified that the highly technical aspects of haemodialysis treatment can be stressful (Vioulac et al 2016) alongside working conditions and the daily routine (Brokalaki et al 2001).

The out-patient haemodialysis setting is dominated by the haemodialysis machines that are fundamental in providing treatment to patients with ESRF/ERF (Faber et al 2003). In these settings, nurses have been observed to have skills which are technology-focused rather than patient-focused (Bennett 2011), having a tendency to treat the patient and the machine together as one unit. Bennett (2011) found from non-participant observation in one haemodialysis unit that nurses dehumanised the patient and this was common practice amongst the participating nurses. These results are from a critical ethnographic study where data were collected from one metropolitan satellite dialysis unit in Australia over a 12-month period throughout 2005. The methods included non-participant observation, interviews, document analysis, reflective fieldnotes and participant feedback. Whilst the study was conducted in Australia, the setting and findings of this study could be seen as relevant to the UK, however the data reported in 2011 was actually collected during 2005. Key changes in practice could have occurred over the last 10 years, so this finding should be treated with caution. In contrast, some patients have actually expressed that they feel the machine is part of their body (Sadala and Lorencon 2006) which might have been the result of nursing approaches to care in the unit, treating them as one.

Schoenhofer and Boykin (1998) have suggested that the caring part of the nursing role is obscured by technology, either in haemodialysis or intensive care environments with the high reliance of machines in both of these roles. Dermody (2006) concurs with this view, believing that with the improvements in haemodialysis technology, less nursing intervention is required. Furthermore, Bevan (1998) argued that nurses are increasingly technologically skilled but have forgotten the caring aspect of their role, believing that nurses in dialysis units are concerned with the production line of patients and are not focused on the patients themselves. Bevan (1998) describes dialysis nurses as 'technologically enframed', where most of the practices and rituals, such as frequent observations, are carried out but not understood or acted upon. The centrality of care and individuality of the patient may then be potentially threatened in these care settings. However, little is known about the patients' perception of technological care in these settings.

One paper suggested the dialysis machine and technology are viewed an extension of the nurse as a caring person (Schoenhofer and Boykin 1998). Patients can also view the dialysis machines as a lifeline (Hagren et al 2001) and have also been described as a means to save a seemingly hopeless situation (Bevan 2000). The machine can cause patients anxiety, with the potential for them not to work correctly and the subsequent impact this could have on their health (Sadala and Lorencon 2006). Much of the writing in this area is now quite dated and whilst the findings of Sadala and Lorencon (2006) are based on 15 participants, it is difficult to assess the rigour of the study as few methodological details are given. The relationship between patients and their machines remains unclear.

2.2.2 Haemodialysis Treatment

The haemodialysis process is 'a lesson in boredom, frustration and pain' (Faber et al 2003 p151). Many articles identified that haemodialysis treatment is a huge aspect of a patient's life (Almutary et al 2013, Kazemi et al 2011, Herlin and Wann-Hanson 2010, Kaba et al 2007, Sadala and Lorencon 2006, Hagren et al 2005, Polaschek 2003, Hagren et al 2001). Treatment can take up to five hours per session, with three sessions a week (Bevan 2000), and can be viewed as a part-time job by some patients (Faber et al 2003). They can feel tied up by the treatment and heavily restricted by it

(Yngman-Uhlin et al 2016, Bayhakki and Hattakit 2012, Martin-McDonald 2003).

Missed treatment appointments are not an option for these patients, since they will not provide the patient with an adequate haemodialysis and therefore will be detrimental to a patient's health (Murphy 2006).

Patients want treatment which can allow autonomy and freedom, and they do not like the idea of being tied to a renal unit (Morton et al 2010). Some patients feel that haemodialysis treatment is about staying alive for their families (Bennett et al 2013a). From interviews with 30 haemodialysis patients, Chenitz et al (2014) identified that 17 of their participants felt dialysis was life-saving, whilst conversely 11 participants described their treatment as a necessary evil. This sample of participants included those who were compliant with their haemodialysis treatment (defined as attendance for treatment) and those who were not, suggesting that despite adherence to treatment, the regime can still be identified as negative or positively.

Therefore, it is not surprising that patients feel that their treatment encroaches on their time and space (Herlin and Wann-Hanson 2010, Murphy 2006). Treatment restricts a patient's movement, as they are required to come to the unit every second day and home haemodialysis is seen as less restrictive in patient's autonomy and dependence (Shaw et al 2015). The illness experience and treatment also affects patients as they struggle to gain a sense of control (Lindsay et al 2014). Interviews of seven participants (five males, two females) highlighted that loss of control can create powerlessness, which can affect the individual and their wider social network and relationships. Despite the gender misbalance in the sample, the results still highlight the concerns for patients of both genders (Lindsay et al 2014).

Patients have concerns about their future with holidays, work and retirement all being affected by having end-stage renal failure that requires haemodialysis (Monaro et al 2014). Patients also have to travel to and from the unit before and after their treatment. This can take some time, depending on the transport options and the location of units with respect to their home, resulting in the patients having limited time for other activities, including work. They feel they have lost time because of dialysis and that their freedom is restricted (Herlin and Wann-Hanson 2010, Hagren et al 2005, Hagren

et al 2001) and they are controlled by the medical regime and their treatment (Kaba et al 2007).

Patients have found it difficult to adjust to the new limitations imposed by the treatment regime on their life and lifestyle (Sinclair and Parker 2009). Seven in-depth interviews with patients aiming to explore their experiences of managing IDWG for individuals on haemodialysis identified that patients found it a constant struggle and experienced significant loss of function and social interaction because of requiring to manage their treatment and restrictions. The participants only included one male haemodialysis patient with the rest being female, however the results are still applicable to practice despite this imbalance in males and females across this sample.

The view that treatment interferes with patients' everyday activities is also evident from the literature, with patients claiming that treatment has had a huge effect on their routines (Sadala and Lorencon 2006, Murphy 2006) and their physical quality of life (Drennan and Cleary 2005). Kaba et al (2007) conducted a study of 23 long-term haemodialysis patients in Greece using a grounded theory approach. Whilst several studies have previously explored the experiences of haemodialysis patients, this study is one of the few to consider the impact of culture on those experiences. However, the majority of the respondents were men and there was limited information about the age of respondents. It was not clear from the paper whether older men had been purposively sampled and if so, what the initial categories and coding was that drove this. From interviews, Kaba et al (2007) found that patients had stopped seeing some friends as their treatment and restrictions were too difficult to cope with;

‘If I go out with John who drinks and eats, I will be tempted and eventually drink...I cannot socialise with him’ (Kaba et al 2007 p869-870).

They also reported results on limitations on life, uncertainty and problems relating to symptoms. The finding, being dependent on ‘life-sustaining technology’ (Kaba et al 2007 p870), highlighted the machine playing a central position which dominated the space in the unit and was a constant reminder of their kidney disease.

Fluid restrictions also affected social lives, particularly those whose social events had a strong focus on socialising around tea, coffee and going out (Bennett et al 2013a). A consequence of the patient having a disrupted life around their haemodialysis treatments is non-compliance and non-attendance for their treatment (Bennett et al 2013a, Murphy 2006).

From a hermeneutic-phenomenological study exploring the lived experiences of fifteen patients on haemodialysis, six women and nine men were interviewed in regard to the adherence to treatment and quality of life in Chile. Guerra-Guerrero et al (2014) found from this research that patients felt their whole life changed, they were trying to avoid their kidney disease and the haemodialysis treatment then modified their existence. The next of kin or significant others of haemodialysis patients also felt confined by renal disease and this necessary treatment (Ziegert and Fridlund 2001).

Patients have felt they were merely 'receivers of treatment' (Sadala and Lorencon 2006 p139). Their phenomenological study, with 15 haemodialysis patient participants who attended for treatment in a public hospital in Brazil participated in an interview, found that patients felt that medical staff and nurses had imposed the haemodialysis treatment on them, and just had to accept it and suffer. This suggests that patients were not involved in decision-making or in their care. This study also reported anxiety felt by patients due to concerns that the machine may fail and treatment would be inadequate. This reliance on technology to stay alive and well is a key concern for dialysis patients.

The haemodialysis treatment and renal failure has also been found to evoke fears in the patients (Yu and Tsai 2013, Herlin and Wann-Hanson 2010, Hagren et al 2005). These fears were pain, being admitted to the hospital and complications with fistulas. Patients also reported fear about their future. When interviewing seven chronic haemodialysis patients, the prospect of life dependent on haemodialysis left the participants feeling as though there was no future for them. They reported feeling fear and shock and they had found themselves in a place of uncertainty (Calvey and Mee 2011). Patients should feel supported in their treatment with anxiety and fear alleviated by treating each patient as an individual.

Research conducted by Calvin (2004) to explore decisions about end-of-life treatment (e.g. cardiopulmonary resuscitation, mechanical ventilation) in people with kidney failure undergoing haemodialysis. This work was a grounded theory study conducted in the US, with 20 patients participating in interviews. However, only 12 of the interviews were recorded and transcribed and analysed. Calvin reports that the remaining 8 interviews were used for selective coding only. Several patients refused to participate in this study, perhaps as they felt uncomfortable about the topic, so their views may be somewhat different to those presented in the findings. It is interesting to notice that in this study, patients were found to want to continue with treatment and resuscitation as an option until their haemodialysis no longer works. This potentially indicates the treatment is vital to them, and they will not give up until it will not work anymore. Patients stated they do not want to pursue advanced directives or do not resuscitate (DNR) form whilst haemodialysis was still a viable and working treatment option. This is an important aspect to ensure awareness of this topic by nurses and it also indicates the requirement that haemodialysis patients need an approach which will explore their needs and wishes (Calvin 2004).

Recent research conducted by Lazenby et al (2017), identified that prognosis is not usually discussed, due to the belief that haemodialysis patients do not want this information. From thematically analysing 20 interviews with doctors and nurses from a large UK hospital, this research highlighted that withdrawal is not commonly discussed, particularly with the well haemodialysis patients.

Interdialytic weight gain (IDWG)¹ and fluid restrictions were identified as a ‘constant struggle’ for patients (Sinclair and Parker 2009). Educational programmes, either group sessions or video education, have both been identified as being able to bring about an improvement in a dialysis patient’s dietary and fluid compliance (Baraz et al 2010). Providing verbal and written enforcement and education of fluid intake limits has been shown to decrease fluid gain in patients who gained more than 2.5kg between their dialysis treatments (Barnett et al 2008). In opposition, Casey et al (2002) could not conclude that the enforcement of restrictions improved IDWG,

¹ Interdialytic weight gain (IDWG) is the fluid gained between haemodialysis treatments and is usually required to be removed as part of the haemodialysis treatment.

highlighting the complexity of education and support to this patient group with varying outcomes.

In an experiment in Taiwan considering phosphate levels in haemodialysis patients, researchers offered a variety of different interventions to a control group of 47 patients; this included nursing instruction, supported by an educational pamphlet, with instructions on a low-phosphorus diet and use of phosphorus binders, medication reminder cards and by self-recording their diets. After following these different options of instructions, the experimental group exhibited a significantly lower phosphorus intake in their daily diet and milder pruritus compared with the control group (Cheng et al 2017). There were 47 participants in the control group who presented the same systematic nursing instruction as that of the experimental group after the post-test, in line with ethical procedures. Interestingly, the control group were patients who attended on Tuesday, Thursday and Saturday dialysis pattern, whereas the experimental group were the patients who attended the Monday, Wednesday and Friday sessions. This way of splitting the participants may have had an effect on the research, as it was not randomized. The session which patients regularly attend for dialysis can be a choice but also relates to medical needs. Attending Monday, Wednesday and Friday, when medical staff are usually more available, may be due to the medical concerns and their compliance with treatment and therefore may have an impact on the experimental group and therefore could have affected the results.

Various identified research shown here does illustrate that the requirement for educational needs are varied, as some options may work well for some patients and not for others. Interventions such as cognitive behavioural therapy have been used successfully to help patients in fluid restriction compliance, and this is potentially something which should be explored within many dialysis units (Nozaki et al 2005) as part of the treatment and care in the area.

In contrast to focusing on a nurse's involvement and the effect they can have on a patient's diet or fluid intake, other research has suggested that the family carer involvement within a patient's diet has helped reduce haemodialysis patients' IDWG, potassium and significantly reduced phosphate levels (Cicolini et al 2012).

In a phenomenological study, Tanyi and Werner (2008) studied a small selection of women in the USA who were adjusting to the disease of ESRF and receiving haemodialysis treatment. This study did not look at nursing care as it just explored the patient experiences, which did not highlight nursing or nursing care. The patients began their dialysis journey with the appreciation that the treatment improved their health.

The study then identified that patients progressed to have negative views on their treatment: taking up time, long hours, sickness, fatigue, access issues and the potential or actual complications. Comments like:

‘I really don’t like it but I don’t have no choice’ ... ‘the time is what really gets on my nerves you know, because I get itchy and edgy’ (Tanyi and Werner 2008 p48)

have indicated the treatment has negative and undesired effects.

From an audit of Turkish patients and their haemodialysis treatment, Ludvigsen et al (2015) have suggested that 60% of patients received fluid removal rates which were too high. The fluid removal rates have been considered as one way in which to estimate the quality of treatment and of haemodialysis/nephrology nursing (Lindberg and Ludvigsen 2012), as nursing staff control the fluid removal and subsequent rates. Daily dialysis, rather than every second or third day, has been shown to have a positive impact on quality of life and also a decrease of treatment complications (Rayment and Bonner 2008), however this practice is not common in in-centre haemodialysis, particularly within the UK.

Research has identified the many challenges that patients face as part of their haemodialysis treatment. With various views on treatment, this highlights the complexity for patients who require haemodialysis on a regular basis to stay alive. The negative views, in particular, can emphasise the specific challenges that patients can face due to this necessary treatment and that nursing staff require to support patients with.

2.2.3 Symptoms

Patients face many challenges with the technology of haemodialysis treatment including the loss of autonomy, the time it takes, the lifestyle changes and the threat to their own mortality. It has been argued that nursing practices to help patients in these aspects of care are not always a feature in current research. Furthermore, patients have a range of symptoms to deal with and the role of nursing care within this warrants exploration. Few studies report on how the patient experiences nursing care beyond the technological aspects during the process of dialysis.

CKD patients experience multiple symptoms due to both treatment and the disease. (Almutary et al 2016a, 2016b, 2013, Polaschek 2003a). Fatigue has been a major problem described by other studies for haemodialysis patients (Letchmi et al 2011, Kazemi et al 2011, Kruger 2009). Examining the symptom of fatigue as experienced by a group of 39 adult haemodialysis patients, a descriptive correlational design was used to examine fatigue from an inductive approach, considering relevant physiological, psychological and situational variables. Data were collected using a structured self-report questionnaire and biochemical data from retrospective monthly blood tests. The sample size limits the extent to which the results may be generalized to the wider haemodialysis patient population. However, it is apparent that fatigue is a major symptom experienced by this patient group. (McCann and Boore 2000).

Fatigue has been reported as one of the most distressing symptoms (Axelsson et al 2012a) and it has a significant impact on patients and their experience (Letchmi et al 2011). Recovering from dialysis treatment took longer and longer (Axelsson et al 2012a) with patients being unable to undertake all their normal daily activities due to this symptom (Bonner et al 2010).

Lack of social support from social networks has led to patients reporting severe levels of fatigue to those who are better supported from spouses, family and friends (Karadag et al 2013). Research has also identified that this level of fatigue also led to patients isolating themselves from others but some had learned how to cope and overcome the fatigue by understanding how it presented in their own body (Lee et al 2007).

Patients have described the symptoms resulting from their treatment would be endured, because they required it in order to survive (Kaba et al 2007). Almutary et al (2016b) suggest that CKD symptom clusters as a way of identifying different aspects of symptoms dimension. Fluid volume, neuromuscular, gastrointestinal, sexual and psychological are highlighted as dimensions where symptoms fit, however fatigue fits into all dimensions, suggesting its high importance and its significant effect on all aspects of a patient's life. Similar and related work shows that fatigue, pain and sexual dysfunction were highly prevalent (Almutary et al 2016a).

Intradialytic hypotension² was a frequent adverse event and symptom for a haemodialysis patient (Prezerakos et al 2015). De and Xiang Ai (2015) have suggested the implementation of a no food and no eating policy for patients when receiving haemodialysis treatment and argue for in-centre meals to not be provided due to risks of hypotension, aspiration and lack of staff to support this aspect.

There may be a number of symptoms that patients experience as part of dialysis which may become part of the nursing care delivery. Whether the patients or indeed the staff perceive this as part of a nursing role is unclear.

2.3 Haemodialysis Nursing Care

Haemodialysis nursing is:

‘caring for people and maintaining a human and interpretive focus in a practice dominated by medicine and technology’
(Bevan 2000 p442).

The nursing practice in a haemodialysis unit has been described from observations as a mix of authoritarian practices and caring compassionate holistic nursing. Nurses working in the haemodialysis setting need to combine technology and interpersonal skills into the nursing care they provide (Bevan 2000). Schoenhofer and Boykin (1998) found through a single person case study, focusing on one nurse-patient relationship in the haemodialysis setting, that the value of nursing care must be lived

² Intradialytic hypotension is a drop in blood pressure during haemodialysis treatment

and cannot be predicted. They propose that the values experienced are unique and that patient-centred care should focus on the patient and their specific needs. Renal nursing has been described as a response to the client experiences and developing a relationship with the patient (Schoenhofer and Boykin 1998). Whilst this is a useful insight, the single case study approach is of limited value and presented without addressing rigour. In contrast to these findings, Bennett (2011) argues for the concept of technological intimacy where the nurse is concerned primarily with routine technological tasks and hence care is dominated by technology. Whilst Bennett's work draws on an earlier ethnographic study (Bennett 2009), it is unclear in the 2011 paper to what extent the arguments are premised on empirical findings.

One role of the nurse in haemodialysis is to humanise renal replacement therapy, although this does not necessarily happen in practice, as nurses have been shown to be more concerned with the machine (Bennett 2011).

Patients appreciate staff who are easily approachable and understanding of their needs and situation (Bath et al 2003). Patients have suggested in one piece of research that some nurses are like robots, which has a negative effect on patients (Al Naszly et al 2013). This contrast between how staff are perceived within haemodialysis units highlights the importance of the nurses and other healthcare professionals in their approach to the job, work and patients.

Dermody and Bennett (2008) conducted focus groups, which were then followed up with the same participants, using a generated questionnaire to explore stress in two haemodialysis units in Australia. The questionnaire was developed from the focus group data and also used relevant literature. Despite a small, limited sample size of 19 nurses, 12 in-centre and 7 satellite nephrology nurses, this research identified that on a daily basis, nurses felt that they did not have enough time to discuss problems and educate patients, which resulted in high levels of stress. All 19 participants did identify that they rely on the other nurses to talk about the stressors or challenges of their work. The research sample did not consider any other members of staff in this area, although it is unknown if there are unregistered nursing staff who provide care in this particular environment. The results indicate that the main stressor for in-centre nurses was lack of time, whereas the stressors for satellite unit nurses came

Perceptions and Experiences of Direct Patient Care from patient behaviour and unrealistic expectations of patients (Dermody and Bennett 2008). The results, particularly the in-centre nurse responses, highlight that the nurses in these haemodialysis units would not have time to provide patient-centred care, and indicates the need for implementing ‘releasing time to care’ or other efficiency programmes within this setting. Despite the small sample, consideration of these results for wider population of dialysis units and staff is required to be considered for patient care and experience.

Figure 6 shows an illustration used by Doss et al (2011) to highlight all the demands on a haemodialysis nurse, and suggests it is not surprising that nurses have little time to communicate with patients. The task-orientated approach is not in keeping with having the patient at the centre of healthcare.



Figure 6: Nephrology Nursing Practice (Doss et al 2011)

A new model for nursing care for ESRF patients has been devised in the USA and is based around the patient, providing education, support and more efficient communication (Neyhart et al 2010). This model puts patients in the centre of their

Perceptions and Experiences of Direct Patient Care care (Figure 7). This model supports a patient-centred approach, rather than a task or routine orientated approach to the nursing care of haemodialysis patients.

The model presented from Neyhart et al (2010) highlights a variety of roles for registered nurses (NP - Nurse practitioner, CKD nurse - Chronic kidney disease nurse), however this model does not include the support staff, or non-registered staff, who are also involved in the provision of haemodialysis in renal units and centres.

The presented model is suggested as one way to systematically approach the care of patients with chronic kidney disease. The various roles allow patients to contact someone at various points within the disease process; for triage, education, and support (Neyhart et al 2010). They present this model of nursing care and suggest it has reduced emergency admissions for patients, as well as improved communication but do not include the data to support this within the paper.

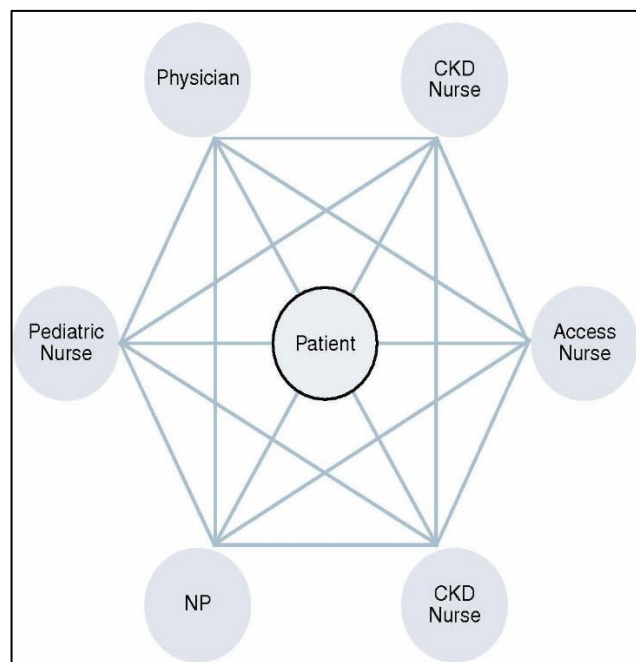


Figure 7: Nursing Model (Neyhart et al 2010)

Dobson and Tranter (2008) have concluded from a literature review on delivering nursing care that primary nursing is the most appropriate method of care in the out-patient dialysis setting to be able to provide patient-centred care. Primary nursing is where one registered nurse is allocated a group of patients, and where the nurse becomes the spokesperson for the patient in this setting. This is different from

allocated nursing where one nurse is to deliver total care. A limitation with allocated nursing is that the nurse may not be on shift, and other nurses may not be able to take over with the care. However, in primary nursing, there are a group of associated primary nurses who assume responsibility if the primary nurse is not available. This allows the patient to have a key nurse, but with others standing by who can continue a therapeutic relationship if necessary.

Nursing or patient-centred care is not just within the walls of the unit (Bennett 2011). It involves the community and complex social and healthcare relationships, although this is an area which has been highlighted as requiring attention. Nurses have reported that they have very little involvement with patients' next of kin (Aasen et al 2012c). Other research has also identified that expert patients felt that an area of care that needed to be developed was to involve their families in haemodialysis care and treatment (Blomqvist et al 2010). Aasen et al (2012b) identified that next of kin reported having little or no dialogue with the healthcare team, and some had to fight to be involved in the decision-making processes.

Staff and social interactions were considered as positive aspects of haemodialysis therapy by 40% of HD patients in a study by Juergensen et al (2006), when they were considering both PD and HD patients across four different local sites in the USA. 146 patients completed questionnaires, which included 84 in-centre haemodialysis patients. These patients cited in free text portions of the questionnaire's negative aspects of haemodialysis. These most frequently included the length and frequency of treatment, fatigue and sickness and needle and access issues in opposition to the positive aspects of staff interactions and the social aspects. Haemodialysis patients in general were less satisfied with treatment than the PD participants and PD patients are more satisfied with their overall care and believe it has less impact on their lives.

Listening to patients was identified as a key aspect of the job of a nurse. (Bonner and Lloyd 2011). In-depth interviews with six experienced renal nurses in Australia identified that information gained from listening to the concerns of patients was extremely important, as was assessing patients prior to, during or after each haemodialysis session. The focus on only experienced users within this research only presents the views of this group, and does not consider the opinions of newly

qualified nurses or nurses who have little renal experience. Nurses are also important for haemodialysis patients as they identified from interviews with this haemodialysis patients. Patients expressed that nurses are key in making them feel safe, particularly through the trust patients have in them and in their presence (Lovink et al 2015).

To explore patients' experiences whilst on the kidney transplant waiting list in Sweden, Yngman-Uhlin et al (2016) conducted interviews on a small, purposeful sample of eight patients who had been undergoing haemodialysis treatment for at least six months and were waiting for a kidney transplant. From the descriptive analysis of the interview data, it was identified that healthcare professionals were required to be available and be good listeners as part of the support needed by patients on haemodialysis who were waiting for a kidney transplant (Yngman-Uhlin et al 2016). Despite the small sample size, the results still highlight an important aspect which impacts on patient experience for this particular group of hemodialysis patients.

Quantitative research has identified that patients on haemodialysis report having positive opinions of nurses and have been satisfied with nursing care (Martin Gurrero et al 2012, Wasserfallen et al 2006). In a large quantitative study by Wasserfallen et al (2006), nursing care was highly rated by chronic HD patients in western Switzerland. 455 questionnaires were returned, an 82% response rate, and for this particular question no patient used the most negative response and suggests some concern with its validity.

The work conducted by Martin Gurrero et al (2012) utilised a questionnaire where 10,632 HD patients responded who were treated in NephroCare Clinics across 335 units in 19 countries (Italy, South Africa, Poland, Hungary, Romania, Slovakia, France, Spain, Hungary, Czech Republic, Turkey, Germany, United Kingdom, Ireland, Slovenia, Russia, Serbia, Bosnia–Herzegovina and Portugal). This questionnaire focused on various elements of satisfaction, but the attention that patients received from nurses was viewed as positive, with the average response between strongly agree and agree, the two most positive options on a seven point Likert scale. Both of these quantitative research papers are unable to provide any

detailed or in-depth data on the satisfaction with the nursing or nursing care provided in these centres. Research by Chenitz et al (2014), which interviewed 30 patients, both adherent and non-adherent to treatment, identified that patients were satisfied with the nursing care that they received. The patient participants were deemed non-adherent to dialysis if they missed six or more treatments in a six-month period. Interviews were conducted either before or after a patient's dialysis treatments in a private room at the dialysis unit or as a telephone interview. The interview responses were then coded based on the researcher's expectations, expertise and the literature affecting the trustworthiness of the results presented.

As part of the research, 18 patients mentioned in their interviews that they were satisfied with the nurses and technicians; this included 10 from the adherent group and 8 from the non-adherent group. 25 patient responses highlighted that they felt well taken care of overall. Factors such as nice personalities, being attentive and making patients feel comfortable were identified as positive aspects. Patient participants commented that staff being gentle and supportive regarding cannulation was a positive aspect of care (Chenitz et al 2014). The findings are limited by the small sample size, single institution, and single geographic region and therefore not necessarily generalisable to wider populations. Also, patients who refused to participate may have different barriers to haemodialysis attendance than the patients enrolled. Interviewers were also not blinded to the participants being adherent or non-adherent, which may have affected the interviews and caused some bias in the questioning or analysis.

Nephrology nurses are ideally placed to support patients and family. Ran and Hyde (1999) suggest nurses act as care-givers, but also as facilitators, mentors, referral agents, educators and advocates. One particular aspect of nursing care which has shown to have positive outcomes for patients is nutritional screening. This led to an increase in referrals to dieticians and an improvement in phosphate levels in haemodialysis patients (Bennett et al 2013b).

In pre-dialysis patients with CKD, encounters with healthcare staff needed to be personalised and individualised to facilitate trust with the staff (Nygårdh et al 2012a, 2012b, Nygårdh et al 2011). Vitri et al (2001) identified communication problems

between nurses and patients, as nurses felt that there was open communication, however, patients did not feel this was the case. This research used the Moos Ward Atmosphere Scale comprising of 100 true and false questions, taken anonymously by 93 nurses and 97 patients. The research states that nursing staff and patients had significantly different perceptions on five categories of questions; openness and sensitivity, staff attitude, order and organization, mutual support and new treatment approaches. Despite the convenience sample of patients in a good state of health, the study was conducted nationwide using participants across 16 haemodialysis units in Israel, which reinforces the generalisability of the findings.

Haemodialysis patients have emotional and informational needs and healthcare professionals are one group which can provide this support (Lai et al 2012). Following interviews with 13 established HD patients in Singapore, phenomenological analysis identified social support, along with emotional distress and treatment related concerns, to be significant for this cohort of Chinese and Malay patients. Despite the difference in healthcare systems and culture to the UK, these results are still important to consider, due to the significant similarities in the treatment plans and therapeutic approach by staff.

Due to the success in some educational programmes, nurses are in a favourable position to provide behavioural therapy and education (Lindberg et al 2011). Patients wanted nurses to discuss and remind them about their diet and their CKD when they were on the machine (Al Nazly et al 2013). Nurses focus on patients as individuals and provide supportive conversation, but they lack the knowledge to support suffering (Stureson and Ziegert 2014).

Bonner and Greenwood (2006) established three levels of nephrology nurses, expert, experienced non-experts and non-expert nephrology nurses. Non-expert nurses had a focus on more task oriented work and had a focus on getting the job done whereas experts were more patient-focused (Bonner 2007a). Less experienced nephrology nurses worked to gain patients' trust (Bonner 2003). Expert nephrology nurses had extensive knowledge gained both from formal education and from their experience in renal and haemodialysis units (Bonner 2007b). Expert nurses also have been identified as blurring their professional boundaries by tasks such as altering

medications for patients, but this was due to a supportive relationship with the medical staff (Bonner and Walker 2004).

The length of time in which nurses have worked in the haemodialysis unit can affect their stress and burnout at work. Hayes et al (2015a, 2015b) have highlighted that working longer in the dialysis environment had a positive effect on perceptions of the work environment, job satisfaction, decreased stress and lower work burnout, whereas Flynn et al (2009) suggest that haemodialysis nurses with high workloads led to occupational burnout and looking for new jobs. Nurses cope with work related stress in different ways (Ashker et al 2012), and find time management, emergencies and the technical work particularly stressful (Vioulac et al 2016). The haemodialysis environment has been associated with stress for nursing staff but haemodialysis units have a positive safety culture, particularly relating to vascular access infections (Davis et al 2016). Van der Veer et al (2012a) established that patients who had worse or poor self-rated health were associated with a more negative experience regarding nursing care, whereas if they rated themselves as very good or excellent, they scored care by nurses higher.

In a quantitative study, exploring the use of Consumer Quality Index for dialysis patients, one of the ten things which in-centre haemodialysis patients valued as extremely important was being taken seriously by nurses. This was the only one of the ten aspects which directly included nurses. This study suggests that patients do not always value time with nurses, as frequent contact from the registered nurse, immediate help from the nurse and the nurses explaining things clearly did not rate high in importance for patients (Van der Veer et al 2012b).

Interestingly, Kovac et al (2002) found that patient satisfaction with nursing staff and technical staff did not affect patient behavioural compliance with treatment and whilst satisfaction is important, it did not affect their decision to turn up for dialysis treatment. Patient outcomes, such as IDWG, vascular access choice and even haemoglobin levels have been shown to be affected by clinical practice which could be linked to the importance of nurses and aspects of the care they provide (Keen 2009).

Whilst nurses in haemodialysis necessarily take a strong technological focus to their work, this can result in care being task orientated. Al Naszly et al (2013) proposes that this had a negative effect on patient care, yet Chenitz et al (2014) and Bennett (2011) found that patients valued skilled and gentle technical care, reflected also in comments from participants in the work by Hagren et al (2001), where patients 'recognised and appreciated competence' p199.

Dobson and Tranter (2008) proposed primary nursing as the most appropriate way of delivering care but this conclusion was not based on any direct empirical evidence. However, Nygardh et al (2011) did find that patients wanted personalised and individualised care, which is one of the central tents of primary care nursing, and have experienced and valued this individualised approach from staff (Hagren et al 2001). Van der Veer et al (2012b) found that patients did not always value time that nurses spent with them and that other ways of delivering care were more important. This idea from patients regarding time with staff is important to consider when exploring direct care in this clinical setting, and highlights the need to consider what care and direct care is for haemodialysis patients in this environment. However, what is clear is that patients' value good communication, being taken seriously and feeling cared for, but how that is achieved is unclear (Vitri et al 2001).

2.4 Relationships between the Nurse and Patient in Haemodialysis

The relationship between the nurse and the patient is crucial for patient care within a haemodialysis setting, and relationships are perceived to be special by nurses (Vioulac et al 2016, Ashwanden 2003). It has been identified that close relationships develop between haemodialysis nurses and their patients (Al-Ghabeesh and Suleiman 2014, Deal and Grassley 2012, Moran et al 2009b).

Work by Wilson et al (2015) highlighted that the patients and staff within a haemodialysis unit acknowledge the relationships and the support that they provide each other. The research likened the unit to a family situation, with some patients taking on childlike roles and staff as more parental positions, and also the opposite where patients, particularly older patients would treat the staff as their children.

Patients have described dialysis staff as significant people in their lives (Bennett et al 2013a), with nurses identifying the frequency of contact as an aspect which helps the development of this relationship (Vioulac et al 2016).

10 haemodialysis patients in Jordan were interviewed using a phenomenological research design. These interviews with patients who had been attending for dialysis treatment highlighted the strong relationship between the nurse and patient, which allowed for patients to feel supported during their treatment, receive education as well as treating their symptoms and provide psychological support (Al-Ghabeesh and Suleiman 2014). The small sample size does affect the potential generalisability of the results, however the detail in the paper on the researchers' conduct and audit trail on the data collection shows the trustworthiness of the data and results presented, including member checking and an additional researcher was engaged in the data analysis and coding process.

The patient should be respected by the nurse (Moran et al 2009b). The relationship has also been described in literature as more like a patient-nurse partnership, where both parties are involved (Doss et al 2011). Patients also expressed that if they do not have a good relationship with the haemodialysis nurse, they find it harder to be treated and cared for by them (Hagren et al 2001). This work explored patients receiving haemodialysis on a dialysis ward in a hospital in Sweden. 15 patients consented and participated in interviews about their subjective experiences with end stage renal failure. The patients were all over 50, but were a mix of male and female, working and retired, and had been on dialysis more than three months, but several had been on dialysis for over three years (Hagren et al 2001). As this work only considers patients who fall in this older adult population, some concerns hang with considering this result across the younger dialysis population, but it does still suggest the crucial role of a haemodialysis nurse for these patients.

Power in the relationship between healthcare team and the patients has been identified as an important aspect of haemodialysis care. Aasen et al (2012c) conducted research which acknowledged that nurses felt they had a lot of power in the relationship, however they used their professional knowledge and endeavoured to keep their patients well, and viewed it as a positive aspect to care. In contrast,

further work by Aasen (2015) highlighted that the power in the relationship between the healthcare team and the patient and next of kin is with the healthcare team and this led to a lack of communication, and poor or one-sided communication.

Moran et al (2009b) has suggested that what she describes as a connected relationship, would facilitate better care within the haemodialysis setting. There are different types of nurse-patient relationships for dialysis settings and there is the potential for the relationship to become over-involved and break professional boundaries. A connected relationship is developed beyond a therapeutic relationship. The nurse and patient have spent enough time together for the relationship to have developed and the needs of the patient have allowed a more mutually 'connected' relationship. The nurse here acts as an advocate and a mediator, but has not lost her professional perspective (Morse 1991). Due to the time a patient may spend with the nurse whilst on haemodialysis, the relationship may develop into an over-involved relationship, where the nurse can no longer maintain a professional perspective (Moran et al 2009b).

Bennett (2011) has found that some nurses described the haemodialysis nurses and patients as 'them and us', and this had an influence on the patient care provided by these nurses (Bennett 2011). From the patient's point of view, however, they have expressed an emotional distance to the nurses (and doctors) in the unit due to limited time for communication (Hagren et al 2005). This illustrates the need for the implementation for 'Releasing Time to Care' allowing nurses to have some time in their daily activities to deliver patient-centred care.

The nurse-patient relationship in haemodialysis is achieved by listening, teaching, using humour and not giving up on the patients. Due to the ongoing relationships, nurses may be required to discuss difficult things, particularly end of life care, as part of their daily work (Morehouse et al 2001).

Communication is essential to develop the nurse-patient relationship that is necessary to provide patient care (Moran et al 2009b). Patients have described nurses as being too busy to communicate (Moran et al 2009b). This is supported by Doss et al (2011) and Figure 6 pictorially represents the nurse and their daily activities. Due to

this high workload, patients expressed that they felt nurses only communicated superficially (Moran et al 2009b). Patients wanted communication from the nurses in the haemodialysis unit; however, they have commented that they are only spoken to when it is in connection with the machine, which has disappointed those patients (Moran et al 2009b). This is in line with studies by Bennett (2011) who have observed that it is the machine that gets most of the attention from the nurses rather than the patients who are attached to it.

Aasen (2012a) found that elderly HD patients needed and were able to trust the healthcare team, however some of the patients felt that the healthcare team might have forgotten about them. They did report they missed the dialogue between them and felt powerless at times. Aasen et al (2012a) suggests the patients' identities seemed to be influenced by this situation, and they found it difficult to be active in their care.

Nursing staff have an impact on patients, and staff who make jokes, laugh and create high spirited environments can help in making patients less anxious and making the experience less routine (Al Nazly et al 2013). However, as this study was conducted in Jordan, this finding may be relevant to this culture but less so in other cultures where perceptions of the role of health professionals may be quite different. Patients have also identified, while participating in research using image cards, aspects of their lives that they would not normally discuss with their haemodialysis nurses (Bennett et al 2013a). Despite strong relationships, patients did not always reveal and discuss aspects of their life during their time within the unit and when receiving HD treatment. Patients have identified as feeling totally dependent on the nursing staff, and their relationship is based on this need and on their skill and expertise (Sadala and Lorencon 2006). This may build on the nurses' task orientated approach rather than a patient-centred approach.

When a patient-centred approach is adopted with regards to providing information and education, a patient explained that they felt respected when information is presented in specific ways suited to them to understand, rather than in a generic way (Schoenhofer and Boykin 1998).

65% of haemodialysis nurses stated that they needed bereavement support when a patient withdraws from haemodialysis or dies (Tranter et al 2016). This research further highlights the close relationship which nurses can have with their patients in this unique clinical setting. Nursing staff have identified to require support when a haemodialysis patient dies, highlighting the relationship that can be created between staff and patients who receive haemodialysis, through surveys with 52 nurses conducted in Australia (Tranter et al 2016). A small sample size and the study being conducted only in a single dialysis service does limit the generalisability of the findings to other dialysis units, but the results do still suggest there are requirements for support for staff in this situation.

Kim et al (2016) identified the continuous effort of Korean nurses to establish good relationships with clients. As part of caring for patients on maintenance haemodialysis, nurses made an effort to feel comfortable with their clients as though they were family or friends. Nursing staff aimed to establish and maintain relationships with patients which were both intimate and comfortable, but balanced and equal. The nurses also considered patients almost as friends, and received advice and ideas from patients on their own daily lives (Kim et al 2016).

A different side to the relationship between haemodialysis staff and patients was witnessed by Ashton (2007), during the lull when patients were on the machine. Patients on one particular shift would sound their buzzer to get assistance which he described as being more spurious in nature, compared to the other groups of patients. Whenever staff would sit down with their colleagues they would be summoned again to help with cramp or because they were uncomfortable. Interestingly this happened with a particular group of patients, and did not happen across all the patient groups.

Ashton's piece details the author's experiences working with patients and staff in the field of haemodialysis, and whilst very insightful into haemodialysis practices witnessed as part of the author's job, no ethical or reflexive practice is detailed within the piece and therefore has some methodological limitations.

The relationship between other nursing staff, not registered nurses, within haemodialysis care has not been clearly documented or covered within the literature.

Whilst research has covered different staff and the roles they have in patient care, there was a lack of literature which established the relationship between patients and particularly clinical support workers in this area. It seems that one of the challenges in haemodialysis care is to provide personalised care and develop close relationships with the patients, yet maintain a professional role as a nurse. Doss et al (2011) suggested this should be more of a partnership in care, yet there is no model of how this might be delivered and no empirical evidence to support the claim. Whilst some studies found that there was a risk of overly close personal relationship between patients and nurses, Hagren et al (2005) found that patients in their study reported feeling an emotional distance between themselves and the nurses. This was supported by Moran et al (2009b) who found patients described nurses as too busy to communicate. A culture of care may exist in haemodialysis units as suggested by Ashton (2007) who found that one group of patients routinely buzzed for attention whereas others did not. It was not clear why this group behaved differently to other groups. As such, there is no clear or deep understanding of relationships between nurses and patients in haemodialysis and how these relationships impact on experiences of care.

2.5 Patient Care within Haemodialysis

The literature has indicated that patients are not always involved in their care and they not are treated as individuals with specific needs. Herlin and Wann-Hansson (2010) found that patients wanted to be seen as a real person, not just as a disease. Patients have also described themselves as feeling lonely (Herlin and Wann-Hansson 2010).

Haemodialysis patients wanted to feel individual (Kaba et al 2007, Hagren et al 2001). Feeling individual maintained their autonomy and patients commented that being treated as an individual contributed to the alleviation of their suffering (Kaba et al 2007). Patients felt respected when treated as individuals, for example, when information is presented by nurses which has been tailored for their personal understanding (Schoenhofer and Boykin 1998).

Haemodialysis patients are unique in having a chronic illness which requires spending a large proportion of their week in hospital with nursing support and intervention, as without this their condition would be fatal. This situation has serious impacts on the physiological, psychological and socio-economic aspects for them and their family (Talas and Bayraktar 2004).

Whilst nursing can be viewed as performing specific tasks, Polaschek (2003b) argues that this is not the case within the haemodialysis units. Polaschek (2003b) argues that renal nursing is not just the clinical practical activities. Nurses can develop a relationship with the person living with end stage renal failure on haemodialysis by responding to the experience of the persons living on dialysis, termed as negotiated care.

Female haemodialysis patients have described genuine caring as an aspect of the nurse which they want to see, as part of the provision of spiritual care in the haemodialysis unit (Tanyi et al 2006). Genuine caring was described as including listening, being kind, patient, respectful, being friendly as well as performing their duties 'like they are supposed to' (Tanyi et al 2006 p534). Patients described that caring should allow a better understanding of the patient and this included communication with the patient to help their understanding of the treatment. It also included nurses treating patients in the manner they themselves would wish to be treated (Tanyi et al 2006). All these nursing actions indicate that nursing care in this setting is more than carrying out tasks on haemodialysis patients. Haemodialysis patients have described feelings of mental and emotional distress, which indicates an area which would require direct nursing support and care (Bayhakki and Hatthakit 2012).

Patients have described being unable to talk about emotional issues as there are patients in the same room when they are receiving treatment (Yngman-Uhlin et al 2016). Deal and Grassley (2012) found nurses do provide spiritual care, which they felt was more than psychosocial care. Being on the same level as the patient, providing listening and touch allowed nurses to deliver this spiritual care. A lack of communication with healthcare professionals was identified in a sample of dialysis patients from 66-87 years old. As part of a piece of research which interviewed eight

patients' multiple times over a 12-month period, Axelsson et al (2012b) established concerns regarding thoughts on death and dying when approaching end of life whilst on haemodialysis. The interviews were performed in private settings, as patients may have experienced reluctance to speak freely about their attitudes regarding death, dialysis and their healthcare team in an open, less private space.

There is literature and research around nurses providing more than just technical care in the haemodialysis setting, but the study proposed here could identify if this is occurring in practice through the exploration of direct patient care.

Communication between nurses and patients is viewed as important by patients in haemodialysis settings (Al Nazly et al 2013). One patient case study identified that the nurses carried out tasks silently, not looking at the patients who were in receipt of care (Faber et al 2003). This silent care suggests the potential lack of interaction during a dialysis patient's time when receiving haemodialysis treatment. By exploring patients' views and the experiences related to direct patient care through this research, the silent care described by Faber et al (2003) can be explored and patients' perceptions on this aspect of their treatment identified, although the one case study approach does not provide generalisable evidence and requires further exploration on a larger scale.

Haemodialysis nurses have described not finding time to spend with patients for education and to discuss problems (Dermondy and Bennet 2008). This indicates the requirement for the implementation of programmes like PW or RTC, but the study does not consider the patients' perspective on the nurses' time and if they agree with the nurses' perceptions. Bennett and Neill (2008) describe that nurses have become focused on the quality of the dialysis treatment, rather than interpersonal care. Without exploring patients' views on what they require from nursing care, we are unable to know whether patients view this as a need or problem.

Martin-McDonald and Biernoff (2002) identified patients going through stages as part of a 'rite of passage' in starting haemodialysis. The three stages which patients require to pass through as part of their dialysis process are: separation, liminality and

reincorporation, suggesting that patients will change as they progress with their treatment.

Increased healthcare provided support improves adherence in haemodialysis (Oh et al 2013). Individual self-efficacy training delivered when patients are on haemodialysis led to better fluid compliance and fewer weight gains between treatments (Tsay 2003). This improved adherence continued for six months following the intense training from specialist nurses.

Haemodialysis patients spend a lot of time within the haemodialysis unit, as treatment lasts for several hours, multiple times a week. Moran et al (2009a) identified that patients used TV's and other activities to pass time and relieve the boredom experienced when they are receiving their haemodialysis. The presence of nurses to provide education, support or social conversation was not identified by the patients as a way to relieve boredom, as they highlighted dissatisfaction with superficial communication from the nurses. The study suggests that patients need a connected relationship due to the long-term nature of the relationship, rather than an over-involved or a therapeutic relationship (Moran et al 2009a). The research proposed will allow the exploration of the direct care patients receive, and the relationship with nurses may be an issue they value.

Haemodialysis units are dominated by equipment and machines, and the technology has an impact on the nurses and patients, which therefore may have an impact on the direct care provided within the setting. Bennett (2011) has described the physical closeness which develops in a highly technical area between a patient and a nurse, termed 'technological intimacy'. He explains it is an 'overlooked and undervalued feature of haemodialysis nursing' (Bennett 2011 p251).

The role of the nurse has an important role in haemodialysis outpatient care and the patient's feelings of safety. Lovink et al (2015) interviewed haemodialysis patients and their findings suggested that feeling safe from emotional and physical threats was important, and that the nurse has a huge impact on this feeling of safety when receiving treatment.

Blomqvist et al (2010) revealed expert patients reporting as being satisfied with care as part of a participatory action research project; four haemodialysis patients were included along with experts in focus group discussions. This small selection of patients also revealed that providing access to results, timely information provision, and for staff to increase their understanding of the challenges of dialysis patients would improve their experience. Haemodialysis patients have reported instances where no members of staff were able to empathise with them as a negative aspect of care. These areas were short-staffed, resulting in a negative patient experience (Bath et al 2003).

Research to date seems to suggest that patients value being cared for as an individual person, feeling that it maintains their autonomy (Herlin and Wann-Hansson 2010, Kaba et al 2007, Hagren et al 2001, Schoenhofer and Boykin 1998). However, little is known about how to deliver this type of care and which particular aspects patients truly value. Tanyi et al (2006) attempted to describe aspects of ‘genuine caring’ in their study, but the population was all female and predominantly African-American. The study was also focusing on aspects of spirituality, rather than exploring experiences and conceptions of caring. One aspect they did mention was the importance of nurses being with and alongside the patients. This was not necessarily as part of technical or even non-technical care and could be an undefined aspect on direct patient care. Yet others have described ‘silent care’, where nurses are either working with machines or even providing direct care without interaction (Al Nazly et al 2013). Again, it is unclear whether patients experience this as ‘caring’ and person centred or whether this can be considered direct patient care if there is no interaction with the patient. How patients experience Bennett’s (2011) account of ‘technological intimacy’ has not been explored.

It has been identified that whilst there is some literature on different aspects of nursing care and patient needs and perspectives. There is little research on the patient experiences and perspectives and some debate on that of the nurses and support workers during their time within the haemodialysis unit, which illustrates the need for this research.

2.5.1 Waiting for a Transplant

For haemodialysis patients waiting on a transplant, different difficulties have been identified. Attending for dialysis was problematic. Patients felt tied up with treatment and immobilized due to the machine and treatment (Yngman-Uhlin et al 2016) and the waiting was difficult due to the uncertainty (Urstad et al 2012, Moran et al 2011). For Korean patients, waiting included being pulled between excitement and frustration and it being a 'light at the end of the tunnel' in getting them off dialysis and hopeful for a normal life again (Chong et al 2016). Swedish patients highlighted the haemodialysis treatment was also a way of facilitating the waiting (Yngman-Uhlin et al 2016) and some patients have viewed the kidney transplant as a form of hope (Martin-McDonald 2003). Moran (2016) has identified patients being anxious, feeling like they are living in limbo and trying to overcome distressing moods and suggested that they are difficult emotions for haemodialysis nursing staff to contend with when patients attend for treatment.

2.6 Patients and their problems

Haemodialysis patients have been identified by Krespi et al (2004) as not being able to explain why they now had renal failure and having poor understanding of their treatment. They had misunderstood the effects of their diet and fluid restrictions on their body and its relevance to their haemodialysis. Patients' needs also change as they remain on dialysis for longer (Bayoumi 2012). 50 adult patients attending a dialysis unit reported that their need for self-actualisation increased with a longer duration of dialysis.

Patients feel mental and emotional distress as part of their dialysis and renal failure experiences (Bayhakki and Hattakit 2012). This meth-synthesis considered 10 qualitative studies on the lived experience of haemodialysis patients. The studies were conducted in western countries, such as the United States, Brazil, Sweden, and Greece, and one study was conducted in Taiwan. This meta-synthesis appears robust due to the significant detail presented in the decision-making processes behind the review.

Considering other research, from exploring experiences of Hmong patients, this particular cultural group felt worthless and unable to perform their roles and responsibilities due to their renal failure and their need for haemodialysis (Kruger 2009). Schick Makaroff et al (2013) highlighted that for CKD patients, including haemodialysis patients, there were unspeakable aspects of their experience of CKD. The participants suggested that some things are never said, and living with death, aspects which were unthinkable and unknowable made it a difficult experience.

Patients have reported sexuality concerns due to being on haemodialysis (Stewart 2013) and others highlighted that physical limitations were a top stressor for haemodialysis patients, with psychosocial stressors being increased with the length of time a patient participant had been on dialysis (Lok 1996).

Yodchai et al (2011) explored how Thai patients adapted to HD treatment. They identified that patient coping included planning and adjustment but also included using their beliefs or religion and being able to live with hope. Argentero et al (2008) have highlighted that patients who have been undergoing dialysis treatment for a long time reported lower levels of satisfaction, potentially due to focusing on more detailed aspects and also potentially as they do not get the same attention as new patients.

The provision of information on haemodialysis was explored by Ormandy (2008). The systematic review identified information topics and needs considered important by end stage renal failure patients. There were 13 topics identified. The review does not explore how to deliver the information to the patients; it just defines the patients' information needs. These needs acknowledge the patient support organisations, psychological impact and family and social life balance. All these are part of a patient-centred approach.

Other research identified that after conducting in-depth interviews with five patients, there were two types of patients who received haemodialysis. Despite the small numbers included from satellite dialysis units in Australia, the first type of patient adopted a received view of information, who do not question their condition and passively accept information. In the other type of patient, they were found to be

engaged; they actively identified their information needs and quickly learned what that they needed to ask and who to ask (Bonner and Lloyd 2012). This research highlights the significant differences between patients when considering the information practices of this population, despite the small sample size, and offers significant insight into this area of patient experiences, despite being limited with the generalisability of the results.

Patients felt limitations on their lifestyle from the food and drink restrictions as well as from the treatment (Kaba et al 2007). Yeh et al (2008) also identified this patient group to have high levels of stress, which could be down to their lifestyle changes and restrictions.

Patients have felt angry and annoyed over various aspects of their care and treatment (Hagren et al 2005). Murphy (2006) looked at a specific patient who attended for haemodialysis. The patient in this study described mood swings including anxiety, anger and frustration, and the potential to lead to non-compliance with treatment and fluid and diet restrictions. This single case research, whilst having significant issues with its generalisability due to its single case approach, does offer insight into patient experience which requires to be considered.

Psychological problems were a focus of some research studies and informative articles (Partridge and Robertson 2011, Dobbles et al 2010, Major and Glass 2010, Lii et al 2007). The psychological impact on patients on haemodialysis is well-documented, but as part of patient-centred care, this should be assessed in all patients and appropriate treatment used as required. Haemodialysis patients surveyed on their experiences of fatigue, highlighted the link between patients with depression the reporting of significant fatigue (Bai et al 2015). In this self-reported study, convenience sampling of 193 haemodialysis patients in six centres participated. The study had very strict inclusion criteria, and details on how many potential participants did not provide consent is not detailed. The sample included patients who had been on HD for at least three months, over 20 years old and did not have depression, cancer or dementia, therefore limiting the population included. Whilst these exclusion criteria allow a focus specifically on the impact of dialysis and no

other co-morbidities, it does limit the generalisability of the results to other groups of haemodialysis patients and requires further consideration.

When patients begin haemodialysis treatment they have been unprepared for treatment. There was a lack of mental and physical preparation during the early haemodialysis experience (Monaro et al 2014) and they were overwhelmed by shock and grief. Yu and Tsai (2013) found diabetic patients went through a stage where they felt dialysis is a disability where they would lose their job and place extra burden on their family. Having no choice but to accept treatment and have haemodialysis resulted in feelings of frustration and hopelessness for the patients. Laughter yoga whilst patients are on HD treatment has been suggested to help improve happiness, mood and optimism and also intradialytic hypotension (Bennett et al 2015a, Bennett et al 2014).

A high prevalence of anxiety and depression were identified in a quantitative study of 53 haemodialysis patients (Partridge and Robertson 2011). Higher levels of body image disturbance than the general population were also revealed in this study although no conclusion can be drawn about the reasons for this, due to the quantitative nature of the study. It does indicate, however, the nursing need for individuals who are struggling to cope with changed bodies and altered lives due to haemodialysis. Body image concerns, particularly related to negative feelings about fistulae was reported by adolescent dialysis patients in Turkey (Baskale and Baser 2011). They also reported feeling different from friends and peers highlighting issues for patients to contend with and require support with. This work only focuses on 18 adolescents aged 12–20 with data collected through interviews. The semi-structured interview technique was used to obtain data about the experience of adolescents receiving HD who had been on dialysis for at least 5 months. The same open-ended questions were asked by the researchers in the same sequence, to add to the reliability to the study.

Another quantitative study indicated the high rates of depression and suicidal ideation in haemodialysis patients in Turkey (Keskin and Engin 2011). The use of group intervention has been shown to improve depression levels in patients (Lii et al 2007). Different coping styles can also impact on depression (Welch and Austin

2001). The use of avoidance coping strategies has been shown to increase depressive symptoms in haemodialysis patients. By not including patients with existing depression in the quantitative study, the participants increased their depression levels at the second analysis three months later, indicating an at-risk group of patients. Nurses as part of patient-centred care should help these patients in ensuring they are supported and coping well.

Research identified that male patients with chronic renal failure rely on the assistance of supportive others rather than cope with their illness in isolation (Cormier-Daigle and Stewart 1997). Thirty adult haemodialysis-dependent males with end-stage renal failure were selected to participate in this small Canadian study. These supportive others comprised family members and/or relatives, friends, health care providers, and spouses or partners highlighting the various supports used by this patient group which includes nurses as healthcare providers.

Peer-support has also shown positive outcomes for haemodialysis patients. Hughes et al (2009) has suggested that an encounter with a peer-supporter can support a patient, particularly for information needs and as part of emotional support.

A qualitative study by Hagren et al (2005) focused on Swedish haemodialysis patients, with some comments from patients discussing their suicidal ideation ‘almost jumped the other night- from the balcony’ (Hagren et al 2005 p297) as the patient states they were distressed so much by their symptoms. Nurses should be aware of the consequences of the treatment and side effects, and provide support to these patients. The referral to a psychiatrist or clinical psychologist may also be appropriate and nurses should explore this option with the patient (Dobbels et al 2010).

Depressive symptoms have also been shown to potentially indicate IDWG which can have huge implications on the patient’s physical health (Taskapan et al 2005). Nurses should discuss this with patients and facilitate understanding on this aspect of their health.

Haemodialysis treatment and the restrictions were identified by patients to put strains on their personal relationships. As the treatment prevented them from living life as they would like to, the consequence of this was strained relationships with their partners (Hagren et al 2001). Patients have stated they have found it difficult to sustain relationships since commencing on haemodialysis (Hagren et al 2001). The strain on these important relationships has led to non-compliance of treatment (Murphy 2006). The acknowledgement of relationships and families as part of patient-centred care should be acknowledged by nurses in the care they provide the patient and their families.

White and Grenyer (1999) patients found their partners were a positive support to them in their HD and renal failure. The family also go through the treatment with the patients, and potentially require to be supported by the nursing staff as well (Hagren et al 2001).

Interestingly, some patients have expressed an optimistic view to life and their haemodialysis treatment, accepting their condition and not worrying about the past or future (Hagren et al 2001). This shows the diversity of all these haemodialysis patients who are dealing with kidney failure in different ways and with different issues. Work by Velesz-Velez and Bosch (2016) has confirmed that for haemodialysis patients, their illness perceptions can have an impact on adherence to treatment and coping styles. Nurses should educate and give information about the disease as this could improve coping and patient outcomes.

Nursing staff have expressed feeling sorry for haemodialysis patients, citing that they feel their life is restricted and the difficulties in complying with their treatment and lifestyle restrictions (Kim et al 2016). Research has suggested that patients have identified in various ways the concerns and difficulties they have to contend with as part of their dialysis and kidney failure, however where the staff, haemodialysis experience and the care provided in this still requires further exploration.

2.6.1 Quality of Life

Quality of Life is a popular measure for haemodialysis patients in research (Danquah et al (2010). Nabolsi et al (2015) identified that quality of life for Jordanian

haemodialysis patients had a moderate decrease in their quality of life, with over half the participants reporting moderate to severe depression. However, Drennan and Cleary (2005) found that there were no differences in Irish haemodialysis patient's mental health than the general population.

Haemodialysis patients have been found to have a lower quality of life (Drennan and Cleary 2005), especially when compared to patients who have received a renal transplant (Niu and Li 2005), or undertake PD treatment (Oren and Enç 2013).

Interestingly, Morsch et al (2006) found that in patients who had been on haemodialysis longer than a year had a higher health related quality of life score than patients who had been receiving treatment for less than a year. This may be due to better adaptation or better acceptance of their treatment and lifestyle. Haemodialysis patients in Greece have been identified to have low scores in various aspects in general health status and aspects relating to their chronic kidney disease (Kastrouni et al 2010). One study identified this population had lower scores in life satisfaction, life achievement, relationships and safety compared to the general population when considering 'subjective well-being' (Bennett et al 2015b).

Patients who have been living long and well on dialysis were identified as being able to restructure their life and transform themselves so as they can maintain a normal lifestyle allowing positive dialysis time and longevity (Curtin et al 2002).

Patients at different stages of the haemodialysis journey may have different expectations and needs. Those in the early stages often felt unprepared (Monaro et al 2014) and there are numerous studies reporting the psychological sequelae to haemodialysis. There is a key role for nurses to support patients facing these issues and to identify and refer those with mental health issues requiring further treatment. However, the patient's views of what they expect or desire and whether nurses also see this as their role and feel prepared for it warrants further investigation.

2.7 Staff in the Haemodialysis Area

Registered nurses and clinical support workers work side by side to deliver patient care within many healthcare settings. Within the haemodialysis environment,

clinical support workers are able to carry out many aspects of haemodialysis care and are an important staff group.

Haemodialysis was traditionally carried out by registered nursing staff in the UK, with the support of the technician. However, within the haemodialysis unit being considered for this research, the role of the technician has become one with a more nursing focus, and is termed a support worker rather than a technician.

Perumal and Sehgal (2003) explored the job role for nurses and technicians within haemodialysis settings in the US and also looked at their patient care practices. The study issued a questionnaire to both staff groups and, along with questions on job satisfaction, were also asked how often they answered questions or explained treatment, were attentive to the social impact or personal impact of dialysis or made treatment or medication errors. 131 nurses and 109 technicians who were involved in patient care responded to the self-reported questionnaire. One area where high satisfaction was recorded for staff was in the domain of personal delivery of patient care, where 37% of nurses and 50% of technicians responded in this category. The study asked centres to select one nurse and technician who would be asked to participate in the mailed questionnaire. Despite the sample size, this is still only a small proportion of staff in the US working in Medicare and Medicaid centres in HD, and only a third of the nurses issued with a questionnaire responded, which suggests limitations when considering the generalisability and transferability of the results. However, the questionnaire appears well developed through pilot testing and adaptation from valid and reliable pre-existing job satisfaction questionnaires, which is a strength of this particular study.

The complexities of haemodialysis patient care have already been illustrated, and suggest there is much more than these three categories. Patient care practices in this study were also self-reported, so the research proposed here would allow for the care practices to be witnessed and a true picture of exactly what patient care occurs can be gained. The study does not explain how technicians are classified, however, from the article it does appear they have more of a nursing remit than a technological one, but this is unclear. The research here allows the inclusion of both registered nurses and the clinical support workers in the consideration of direct patient care.

Technicians are a special category of haemodialysis providers who are primarily focused on performing dialysis in the USA, operating machines and are required to complete specific technician training leading to national (US) certification (Wilkinson et al 2014). Research into different types of workers, who are not registered nurses, has highlighted that in the US, technicians and licensed Nurses both perform 'direct patient care', however, technicians did not administer medications and registered nurses were not included in the study to compare their tasks against these two different staff groups (Garbin and Chmielewski 2013).

In areas where there is a high patient to nurse ratio, more tasks were left undone and higher levels of hypotension reported. More patients also skipped or shortened haemodialysis treatments and the level of complaints was higher (Thomas-Hawkins et al 2008). Westgarth et al (2012) implemented a programme to allow haemodialysis nurses in Australia to look at how they delivered care due to staffing shortages and a change in the workload. The programme was successfully implemented and appears to have improved patient satisfaction by reviewing the way in which care was delivered, however it does not suggest that time with patients was important or improved with this programme.

The role of non-nursing staff in providing supportive care to haemodialysis patients is yet to be explored. Given that these healthcare support staff are involved in technical and direct care, the patient will clearly experience care being delivered by them as well as by registered nurses. Research looking at the patient experience should consider care delivered by people in these roles, as well as those of the registered nurses.

2.8 Conclusion

Historically, research within haemodialysis has expanded knowledge and understanding of the various different elements of patient care and nursing perspectives. However, this literature review has demonstrated there is a gap in the literature and knowledge base that this research seeks to address.

One group of patients who are identified as requiring a large amount of nursing support are those in need of haemodialysis as a form of renal replacement therapy.

Considering the term direct patient care within the setting of a haemodialysis unit will support the generation of understanding of the caring practices which occur in this specialised and fairly unique setting.

What constitutes direct patient care for both patients and their nurses / healthcare support workers has been argued to be unclear. Whilst some research suggests skilled technical care was valued (Chenitz et al 2014), genuine caring is what patients value and want (Tanyi et al 2006). It is also unknown whether nurses concur with this view and actively seek to deliver care in this way. Some patients valued time spent with them whilst others did not, valuing other forms of caring more (Van der Veer et al 2012b). Silent care has been suggested as prevalent in this environment, and the concept of technological intimacy proposed, but there is no research to explain or understand how these are experienced by either nurses or patients (Bennett 2011, Al Nazly et al 2013). Furthermore, there is no clear or deep understanding of relationships between nurses and patients in haemodialysis and how these relationships impact on experiences of care.

The research proposed adds to the knowledge on direct patient care as a term, allows for a greater understanding of this particular area as a whole and adds to the knowledge base of haemodialysis context and practice. It is evident that further exploration of the concept of what direct patient care is to patients and nursing staff within this setting is required.

Elements of care which may be important to patients are potentially missed when using some quantitative data metrics and do not necessarily portray the whole person. They have suggested that:

‘incorporating the voices and views of our patients by introducing more mixed methods and qualitative approaches into our research inquiry, we can optimise the information we obtain to inform practice’ (Morris et al 2016 p72).

It is argued then that research to investigate direct patient care in the haemodialysis unit must incorporate both patient and nursing staff experience and voices to

understand what constitutes direct patient care and how it can be provided in this context.

Whilst there is some extensive literature on different aspects of suggested nursing care and patient needs and perspectives, this study allows for the exploration of all the patient needs from nurses during their time within the haemodialysis unit, rather than specifically focusing on certain aspects of their care.

In conclusion, it is evident from the literature that there is a lack of research into the patient's perspectives of care in this setting. In this setting, nurses and unregistered staff, such as clinical or healthcare support workers also play a part in this care experience. Understanding both the patient and the staff experiences involved in the care provision will allow greater understanding of the haemodialysis experience and the care which can and should be provided. Patient perspectives alongside the views of the nursing staff is crucial in the data collection and research.

Chapter 3 Concepts of Caring

3.1 Introduction

Caring is a concept which has been considered by various scholars over the years, due to its direct and fundamental relation to nursing practice and patient care.

This chapter introduces the concepts of caring as the backdrop to this thesis. Whilst the previous two chapters have introduced the research and considered literature on direct patient care and nursing and patient care within a haemodialysis context, this chapter will explore theories of care and caring in nursing practice. The construct of caring is to be explored in order to analyse the processes and experiences of direct patient care in haemodialysis nursing.

The caring literature is summarised and then a final conclusion to the both literature chapters within this thesis are then presented prior to consideration of the research design in Chapter 4.

3.2 Concepts of Caring and Theories of Care

Caring is a concept which has been acknowledged as difficult to define, and various perspectives have been suggested across the literature to allow greater understanding of caring, and caring within nursing.

Morse et al (1991) began with an analysis of concepts and theories of care (Table 3), concluding that these were underdeveloped and not always relevant to nursing practice. Sourial (1997) has since suggested the avoidance of the use of the term or concept 'caring', due to its vague and complex nature, and suggests the use of 'holistic nursing care' as the term is more defined.

Brilowski and Wendler (2005) suggested that there are five attributes of caring within nursing and Finfgeld-Connett (2008a) has suggested that caring is an interpersonal process which is context-specific. Sargent (2012) has since suggested that despite the numerous conceptual analyses conducted to further develop and understand and explain caring within nursing practice, they have not helped to define it.

Table 3: The Major components of five perspectives on caring (Morse et al 1991 p124)

Caring as a human trait	Caring as a moral imperative	Caring as an affect Interaction	Caring as an interpersonal intervention	Caring as a therapeutic Intervention
Essential for being human	Foundational basis- nurse virtue	Empathy, feeling and concern for another	An exchange characterised by respect and trust	Nursing actions that meet patients' needs
Universal	Nurse-centred	Nurse-centred	Mutual involvement	Patient-centred
Necessary for survival	Maintain dignity of patients	Nurse must feel compassion to be able to nurse	Develop a type of intimate relationship	Implementation meets patient's goals
Essential way of being	Guides decision-making, provides 'oughts' behind the 'shoulds'	Feeling motivates the nurse; nurse feels better when able to 'really nurse'	Process that can enhance growth of both patient and nurse	If actions are appropriate, the patient improves regardless of how the nurse feels
Constant, long-lasting	Constant concern for patient	Nursing is defined in relation to affect, however, affect may vary with kind of patient stage or relationship and/or situational demands	Is likely to vary with ability or desire of patient to be involved with nurse and situational demands	Varies with situational demands and in relation to knowledge and skill of nurse

The seminal work conducted by Morse et al (1991) explored various definitions of caring as part of a comparative analysis of the literature, theories and concepts on caring. Morse et al (1991) identified 35 different authors' definitions of caring, to then further suggest conceptualisations of caring. However, the volume of authors and subsequent five conceptualisations further illustrate that caring is a complex concept. Five different and key concepts of care for nursing practice were identified. These conceptualisations of caring each describe caring in a different way; caring as a human trait, caring as a moral imperative, caring as an effect, caring as an interpersonal interaction, and caring as a therapeutic intervention. These five concepts are now detailed, highlighting important caring theories which Morse et al (1991) grouped into these concepts of caring and are also briefly described in Table 3.

Caring as a human trait claims that caring is a part of human nature and is inherent in all people. Morse et al (1991) cite Griffin (1983), Leininger (1981, 1988) Ray (1989) and Roach (1987) as the four theorists who contribute to this conceptualisation of caring.

Despite not being cited within Morse et al's (1991) work, it is important to highlight within this concept that philosophers such as Heidegger (1962) have also contributed towards this understanding of caring. He has suggested that caring is a way of being; a way of being human. Heidegger (1962) suggests that caring is a fundamental human way of being in the world.

Supporting Heidegger's view, Roach (1987, 1984) and Griffin (1983) have identified that caring is a way of being and part of humanness. Roach (1984) states that caring is the human mode of being, that it is not simply an emotional or attitudinal response. Caring is a total way of being, of relating, of acting, a quality of investment and engagement in the other- person, idea, project, thing, or self (Roach 1984 p2).

Leininger suggested that care is the essence of nursing and it is the central and unifying focus of nursing. She also suggests that care is linked with culture, (Leininger 1985, 1988, 1991, 1995) and that caring refers to actions and activities directed towards assisting, supporting or enabling another individual or group with

evident or anticipated needs to ameliorate or improve a human condition (Leininger 1991).

Caring as a moral imperative reflects the moral commitment to preserve humanity. Watson (1985), amongst other theorists, contributed to this concept of care which is primarily concerned with maintaining the dignity and respect of patients as people.

The concept that caring as an effect is argued by theorists as caring being an emotion, a feeling of compassion or empathy, which motivates care to be provided. This concept reflects the nature of the emotional involvement in caring.

The perspective that caring as an interpersonal interaction suggests that there is a mutual effort between the nurse and the patient. Both parties are trusting, respectful, communicative and committed to each other (Morse et al 1991). Within this conceptualisation, Benner and Wrubel (1989) argue that caring comes first, it is a word used for being connected and sets up what matters or what counts as stressful to a person.

Caring as a therapeutic intervention is where nursing actions can meet the patients' needs and patient goals are important so that the nursing care can meet these needs. Morse et al (1991) describes the theorists within this concept are task orientated, and their descriptions of caring are focused on actions which are identified as caring.

Within their comparative analysis, Morse et al (1991) also highlighted that conflicts between theorists on caring could be reduced to behavioural tasks and nursing actions. Some theorists suggest caring is a moral ideal and not reflected in a set of techniques (Watson 1985, Roach 1987). However, opposing this is a suggestion that actions are indicators of caring and evidence that caring has occurred (Leininger 1981, 1988).

More recently, Boykin and Schoenhofer (1993) have theorised that caring is the intentional and authentic presence of the nurse with another who is recognised as living, caring and growing in caring. The philosophical view from Boykin and Schoenhofer (1993) is that caring is a human mode of being and caring is an essential feature and expression of being human.

It has been suggested that Boykin and Schoenhofer's (1993) theory is grounded in humanism, along with the separate work by Leininger (1991), Roach (1984, 1987) and Watson (1985), and these four theories suggest that caring in nursing is based on human science (McCance et al 1999).

McCance et al (1997) from a concept analysis of caring in nursing has suggested there are four critical attributes of caring – serious attention, concern, providing for and getting to know the patient. Also identified from this concept analysis was that there were antecedents of caring, expressions which give caring meaning - including the amount of time, respect for persons and an intention to care.

McCance (2003) has subsequently produced a conceptual framework following interviews with patients in their own homes after discharge from hospital. This work suggested what is needed for the provision of care (structures) that allow for activities of care (process), and that suggest feelings of wellbeing and patient satisfaction (outcome). From this work, McCance (2003) suggests that there is a linear link or relationship between the structure, process and outcome. The work identifies that there are eight activities or processes of care that constitute caring. Providing for physical needs, providing for patient's psychological needs, being attentive, getting to know the patient, taking time, showing respect, being firm and the extra touch are named as the processes or activities she has suggested which are ways in which to provide care.

Brilowski and Wendler (2005) identified five core attributes of caring within nursing from their evolutionary concept analysis of caring; relationship, action, attitude, acceptance and variability. The first core attribute of relationship concerns the professional caring relationship between the nurse and the patient. This has a focus on trust, intimacy and responsibility. Professional caring almost always has to include some action 'doing for the patient or being with the patient' (Brilowski and Wendler 2005 p643). Within this action attribute, four further actions were identified; nursing care, touch, presence and competence. Nursing care was the actions and interactions between a nurse and a patient; touch was the non-verbal communication using caring touch.

Competence was considered crucial to good care; however, competence alone is not considered to be caring. Presence was not only physical presence; it is the act of genuinely engaging. Presence here consisted of occupying the same space with the patient, listening carefully, allowing time to share and communicating to patients the nurse's interest in them.

Attitude was revealed as the third attribute within the concept analysis as important, due to the requirement of nurses to have a positive attitude to be considered caring. The fourth attribute was acceptance, where the person behind the patient is seen and accepted. Caring was also identified to be a fluid and changeable thing, so variability was the fifth attribute identified, due to this change in caring as the nurse becomes more proficient, or the circumstances, environment and people involved would change and impact.

More recently, Finfgeld-Connett (2008a) through a meta-synthesis of caring has suggested that caring is an interpersonal process which is context specific. This nursing caring process is characterised by expert nursing practice, interpersonal sensitivity and intimate relationships.

Expert nursing is the use of assessment skills and physical, psychosocial and spirituality orientated nursing interventions to identify the meanings of another's situation. Intimate relationships are included within caring as the development of relationships between individuals as protective and trusting.

Interpersonal sensitivity includes the intuitive and empathetic insight into another's suffering. Finfgeld-Connett (2008a) suggests that being physically and mindfully present, focusing completely on the patient and being emotionally open and available are key to this part of the caring process. It also includes going beyond the usual routine and is demonstrated through gestures such as attentive listening, touching and verbal reassurances.

3.3 Summary

The consideration of key literature on caring is important when conducting research which aims to consider care in one particular context. Seminal work by Morse

(1991) began to explore and draw together the various ways in which care has been considered. More recent work has produced further exploration of care through research. Despite this continued focus within research literature, there is still a lack of synergy across the various definitions, indicating that there are still discrepancies across the literature in being able to define care as a term or concept in nursing practice.

3.4 Conclusion of the Literature Chapters

Considering the literature presented across these first three chapters, little is known on the concept of direct patient care; it is poorly understood and operationalised within healthcare. Direct patient care can be understood from what is seen, however this may not reflect patient and staff perceptions and experiences and suggests a gap for research to explore.

Considering haemodialysis units as a particular setting is valuable, because care is experienced on a very regular basis by the same staff and patients, due to the nature of the condition and the treatment options.

Chapter 4 Research Design and Methods

4.1 Introduction

This chapter will detail the approach used to answer the research aim and research questions, to justify the research design and to describe how the research was conducted.

The chapter begins by stating the overall research aim and research questions. It provides the justification for the study and highlights the reason for conducting the study using an ethnographic approach. The underlying epistemology and theoretical perspectives are then introduced and consideration of the researcher's position as an insider researcher is highlighted.

The research methods will then be detailed and discussed, considering participant observations, fieldnotes, photographs and informal questioning alongside semi-structured interviews. The participants in the research study are also introduced, as are the ethical considerations for conducting this study. This chapter concludes with discussion of an important element of ethnographic research: reflexivity, and details the researcher's reflexive practice using examples from the fieldwork and fieldnotes.

4.2 Research Aim and Questions

The aim of the study was:

To gain an understanding of patient and staff perceptions and experiences of 'direct patient care' within one large in-hospital haemodialysis unit.

The specific research questions were:

- To establish what the patients want and value as 'direct patient care' in the haemodialysis unit
- To explore patient perceptions and experiences of 'direct patient care' and interactions
- To establish what haemodialysis registered nursing staff view as direct caring activities for haemodialysis patients
- To establish what haemodialysis clinical support workers view as direct caring activities for haemodialysis patients

4.3 Choosing a Research Design

Within health research, the use of qualitative approaches can allow for the exploration of people, through gaining an understanding their worlds and making sense of their experiences. This differs from the use of quantitative methods, which provide a measurable response, e.g. a randomised control trial. The choice between these two types of research design, and furthermore the specific method or approach chosen within these depends on the nature of the research question.

Within the collection of qualitative methodologies, ethnography is one of the oldest qualitative methodologies and has been used in a variety of disciplines for research. Traditionally originating from social anthropology in the 19th Century (Wall 2014), and whilst overlooked at times for use within health research (Savage 2000), it is now becoming more popular, and this research design is being used to explore and study many different health issues.

An ethnographic approach allows for human events to be witnessed in context. It is a process of learning about people, by learning from them (Roper and Shapira 2000). It involves the researcher participating directly in the setting, in order to collect data in a systematic manner, but without meaning being imposed on them externally (Brewer 2000). Ethnography traditionally aims to be naturalistic, collecting data without influencing or interrupting it by participating in the daily lives of others for an extended period of time. Ethnography is also particularly interested in the culture or setting in which the research occurs (Hammersley and Atkinson 2007).

4.3.1 Consideration of other research designs

A qualitative approach was considered to be more appropriate for this research than a quantitative or mixed method approach, due to the research aim and questions. As the research questions are considering experiences and perspectives, these are more suited to be collected by a method of enquiry where the researcher can build a complex holistic picture through watching, listening and asking questions to illuminate the area of enquiry, rather than exploring the effect of objective measurements (Hammersley and Atkinson 2007), which therefore suggests a qualitative approach to be suitable.

With this in mind, several qualitative approaches were considered before deciding on ethnography. Phenomenology, case study research and grounded theory were also considered as potential research designs for this research and determined research questions. These three approaches will now be considered, to show that whilst they are valuable approaches to qualitative research, why they were not chosen and ethnography was the favoured research design. They can all provide an understanding from the participant's point of view of everyday life, but have differences to consider when making the choice of research design.

Phenomenology describes the common meaning of participants lived experiences (Van Manen 1990). This design aims to reduce individual participant's experiences as they report it into a common experience or phenomenon. It allows the researcher to then describe what participants have experienced and how they experienced it. This design provides a deep understanding of the phenomenon as it is experienced by participants, which would be appropriate to be used for the research questions to describe the essence of the experience.

Case study research allows for a single case to be examined within a real-life context or setting (Yin 2013) which is a bounded case or system (Creswell 2013). The case study approach allows for an in-depth description and analysis of a case studying an event, an activity or different individuals.

Whilst both of these designs have indications as to why they would be appropriate to use for the research questions already stated, there were some potential issues identified in choosing either of these designs. Case study research does not allow the determination of a culture or group, rather just specific cases as illustrations. Phenomenology allows the understanding of an experience or shared phenomenon, but does not necessarily allow for the context or setting to be taken into consideration when exploring the shared experience or phenomenon.

Grounded theory is an approach which moves beyond description to generate or discover a theory for a process or action. (Charmaz 2014, Glaser and Strauss 1967). All participants are required to experience the process and that theory can be generated and grounded in the data collected on this process. Glaser and Strauss

(1967) pioneered this research design, allowing for a general explanation of a process to be shaped by the views of their participants. Grounded theory was considered, but given the researcher's in-depth existing knowledge of the area, there would have been a clear conflict with one of the underlying principles in grounded theory; that of being naïve to the proposed research.

Following consideration of these different qualitative approaches, ethnography was chosen as the design to explore the set research aim and questions illustrated in 4.2. Ethnography was considered the most suitable, as it would allow the study of a group sharing the same setting to describe and interpret the shared patterns of culture (Creswell 2013, Roper and Shapira 2000). Ethnography as a design will now be discussed as to its merits and important considerations in this particular research.

4.4 Choosing Ethnography

Despite considering these other qualitative research designs, phenomenology, grounded theory and case study research were discounted and ethnography was chosen as the research design to be used for this particular research question.

The goal of ethnography is to determine the perspectives of all the participants in the research setting (Atkinson et al 2001, Roper and Shapira 2000). Ethnography would allow the experiences of the entire group to be considered within this healthcare setting and also take into consideration the context in which the care took place, through the researcher's immersion in the setting.

Ethnographic research requires a prolonged, systematic, first hand and direct encounter with the people concerned, allowing the study of them and their behaviour. Ethnography is an inductive approach, providing insight into groups of people and can allow understanding of different worlds (Draper 2015). Challenges within ethnography are due to this immersion within the setting and therefore the researcher is unable to see the entire picture or become too involved in the setting under study.

Key to this approach is to establish the native point of view of the participants, otherwise described as the emic perspective (Malinowski 1922). Ethnography can allow for the collection of rich data from emic (participants) and etic (researcher)

viewpoints. The researcher will allow the observation of situations as they occur, to provide a detailed account. This description can show the understanding on the workings of the culture sharing group and identify patterns or anomalies in the setting and group under study (Atkinson 2015, Atkinson et al 2001).

Ethnography also allows the inclusion of context as part of the research; it is not merely the description of a scene of event, but allows the meaning of the event to be explored and accounted for, considering the participant's own voice (Davies 2008, Atkinson et al 2001). This aspect was crucial for choosing this research approach, as the setting was perceived an important aspect to consider when exploring this research question.

Due to the nature of ethnography to explore the participants and setting to gain their perspectives, ethical issues can arise due to this intrusion into participants' lives as part of the data collection. Potential participants may also consider not participating, due to this perceived intrusion by the researcher, where they do not want the detailed enquiry to occur, which is important in this approach. The researcher must make the nature and detail of the research explicit and in line with ethical procedures, particularly due to the healthcare setting and the inclusion of patients (section 4.1.1 considers fully the ethical standards in this research).

Ethnography can be used in a variety of ways for healthcare research: to explore beliefs, cultures, behaviour or practices, but importantly with reference to the context in which they occur (Savage 2000). The use of an ethnographic approach in healthcare research can allow for long-term participant observation with multi-method data collection (Huby et al 2007).

Robinson (2013) has described ethnography as the 'future of nursing science' (Robinson 2013 p19). This statement shows the real value that some have for ethnography as a research design and what it can bring to research within healthcare and nursing. The thick description (Geertz 1973) and rich data that can be generated through ethnography can allow for a greater understanding of particular health related issues. It can allow the exploration of many health-related issues in a variety of healthcare related settings. This methodology can allow the exploration of health

behaviours within different settings, either primary care or community areas or even patients' homes (Goodson and Vassar 2011, Huby et al 2007). With perceptions and experiences being important for the future and development of healthcare delivery, the methodology can allow for this to be addressed through research.

Ethnography is inductive and versatile (Morse 2016), using flexible and interactive methods to understand the participants' realities and data collection. This data collection is usually a combination of three data collection strategies: participant observation, interviews and documentation (Hammersley and Atkinson 2007). Participant observation is usually the central data collection strategy in ethnography and uses the researcher as an instrument of data collection (Agar 1997). This method of data collection is appropriate, as central to ethnography is the witnessing of what goes on and being involved in the setting (Lambert et al 2011, Hodgson 2000, Roper and Shapira 2000, Savage 2000).

Ethnography should be carried out in a natural setting, which involves the researcher having face to face interaction with the participants, to present an accurate reflection of the participants' perspectives and behaviours (LeCompte and Schensul 1999).

Concerns on ethnography as a research design occur, as it is well understood that the product of an ethnographic research is influenced by the researcher and their participation and position within the field of study. Despite this, ethnography was chosen as the research approach to inductively explore the participants in this haemodialysis unit in relation to the research question.

4.5 Focused Ethnography

Ethnography as a research approach began as a descriptive aspect within social anthropology, which allowed for the uncovering and writing about primitive and unknown societies or cultures (Hammersley and Atkinson 2007). This research design has continued to be adapted by researchers and now is an offshoot from more traditional ethnographic approaches; a further distinct methodology has evolved.

This further development within the ethnography literature is described as focused, mini- or micro-ethnography which still follows some of the traditional elements, but

can allow for research data to be collected by using a pre-formulated question and focused exploration, rather than the complete immersion in a field site for months, with traditionally lacking predetermined research ideas.

Knoblauch (2005) first described focused ethnography; it suggests that researchers are no longer required to travel to far away unknown cultures or places to use this methodology for research. Focused ethnography deals with a specific problem, but has its roots within the traditional ethnographic approach (Wall 2014).

A crucial aspect of a focused ethnographic study is the shorter period of time in the field, compared to more traditional ethnographic work. The shortness of fieldwork can suggest lack of time and ability to uncover participant perspective and the nuances of the setting under research. Despite the shorter time in the setting, focused ethnographic work can still provide trustworthy research data and results, due to this focused approach allowing data to be collected.

Elements of this PhD research are more aligned to focused ethnography, however some aspects remain within the more traditional ethnographic approach. Individual data analysis and significant immersion in the field with intense fieldwork are more traditional ethnographic methods, in contrast to the more focused ethnographic elements, particularly the predetermined research focus. This is key to focused ethnography when the topic of enquiry or research question is preselected, or a specific aspect of the field was studied with a predetermined purpose.

Focused ethnography has been used within nursing research (Cruz and Higginbottom 2013, Higginbottom et al 2013). It was suggested that this methodology is relevant specifically for nursing research, as it can offer a better understanding and appreciation of nursing, particularly due to the predetermined research field or focus and the potential for significantly less fieldwork, which allows research to be carried out within a smaller timeframe (Roper and Shapira 2000).

4.6 Ontology, Epistemology and Theoretical Perspectives

It is not enough to state that an ethnographic approach was used for this research. Ethnography can encapsulate different ontological, and epistemological approaches. The researcher must make their position explicit and demonstrate how they are creating knowledge, although in any case, ethnography provides insight into groups of people and can allow for understanding in different worlds.

Constructionism, or constructivist, is the epistemology where meaning is not discovered but constructed. Constructivism does not believe in objective truth to be discovered, it believes that truth and meaning come into existence in and out of our engagement with realities. Constructionism states that meanings are constructed by human beings as they engage with the world they are interpreting (Crotty 1998).

4.6.1 Symbolic Interactionism

Symbolic interactionism is the theoretical perspective behind the use of ethnography in this research design. It is a label used to identify a distinctive approach to study human life and conduct (Blumer 1969). Symbolic interactionism is an approach to understanding and explaining the human world, and grounds a set of assumptions that symbolic interactionist researchers bring to their methodology of choice, in this case ethnography.

Symbolic interactionism is a philosophical perspective that originated from George Herbert Mead in the early 1900's, which was further developed by Herbert Blumer (1969) and is a social psychological approach to studying the meaning of human action.

Symbolic interactionism emphasised that social researchers must get at the meanings behind social actions, that is the symbolic content of the interaction, to see the world through the eyes of the informants. This can be accomplished by talking to them and developing in-depth descriptive accounts of their interactions that construct social realities through the meanings they develop; this theoretical perspective is much more compatible with ethnographic research (Davies 2008).

Blumer (1969) suggests that there are three assumptions within symbolic interactionism. The first is that 'that human beings act toward things on the basis that these have for them' (Blumer 1969 p2). This can be understood by the way individuals act towards others because of the meaning we interpret from them, such as when you enter a restaurant, there is an expectation that those who approach would-be employees who would ask about reservations, take order and serve food.

The second assumption 'that the meaning of such things is derived from, and arises out of, the social interaction that one has with one's fellows' (Blumer 1969 p2) so despite not having any direct experience of this particular social setting, there are things which individuals would expect from prior social experiences.

The third aspect of symbolic interactionism is

'that these meanings are handles in and modified through an interpretive process used by the person dealing with the things he encounters' (Blumer 1969 p2).

The meaning-making and understanding is a continuing interpretive process, where things may stay the same or change (Blumer 1969).

Symbolic interactionism suggests that reality is perceived as a social construct, produced through ongoing social interaction and only exists within a social context. Symbolic interactionism views human to human interaction, not according to response and stimulus, but through interpretation and meaningful, purposeful action and interaction.

Symbolic interactionism and ethnography have become linked, due to both of these positions having an emphasis on seeing things from the perspective of others, and putting oneself in the place of them in order to see the insider's perspective.

When using ethnography, symbolic interactionism can be used as it directs the investigator to take the standpoint of those studied (Denzin 1978 p99), which is in line with an ethnographic approach. It also considers the situation from the point of the actor, the actor's view of actions, objects and society are studied, trying to see the situation as they see it, and determining meanings of objects and acts which is also in

line with an ethnographic approach. Only through dialogue can one become aware of the perceptions, feelings and attitudes from others and interpret their meanings.

Ethnography is the form of research where a setting is studied as well as those who inhabit it. The researcher, even if familiar with the setting, must treat it as strange or new, as the task is to document the setting, the group, and to get inside of each group of people and learn how they see the world.

Creating a joint understanding or meaning, as opposed to separate meanings, is useful as it is constructed between the two as part of the care provided or experienced- it is not alone or isolated. Nurse-patient interactions, or lack of interactions, can be conceptualised from the theoretical perspective of symbolic interactionism.

4.7 Insider Ethnography

Insider ethnography is the term used to describe research with an ethnographic design, conducted in a familiar setting for the researcher where they are already members. This is in contrast to a more traditional ethnographic work, where the researcher would travel to a distant and unknown land, as an outsider, to discover the culture in this new place (O'Reilly 2012, Hamersley and Atkinson 2007, Roper and Shapira 2000). Conducting insider research as a nurse researcher in their own setting shares an identity, language professional base with staff and patients i.e. the study participants. This is helpful, as there is already a base for relationships with participants and the setting, however this knowledge also presents challenges for the researchers (Asselin 2003).

The strong criticisms of insider research and particularly insider ethnography are largely due to the concerns about trustworthiness of the study, because of the previous membership of the researcher to the group and culture, and their inability to be objective and removed from the research and data. Insider qualitative research has to be conducted with caution. Several authors have raised issues which are unique to insider research, which raises concerns with the trustworthiness of the study (Field 1991, Tilley and Chambers 1995, Thomas et al 2000). Despite this, insider research can allow researchers to be in a stronger position by being able to

blend in more, gain more rapport with the participants and participate more easily with the group (O'Reilly 2009).

A positive to an insider position for ethnographic research is that they are known. An unknown or unfamiliar researcher will be perceived as a stranger and to some extent alien to the group (O'Reilly 2009). By being known O'Reilly (2009) suggests the researcher can get to the real, daily, lived-experiences gained from a superior insider knowledge which had been gained prior to the research as primary socialisation.

Within insider research, it is crucial for the researcher to consider their role and position and guard against what Asselin (2003) has described as role confusion. They recommend the importance in the researcher stepping back from the data collection process and observing themselves as a researcher. Notes kept on their thoughts, feelings and responses to the data collection should be shared with experienced researchers (such as supervisors), to ensure the researcher role is maintained and no breaches of ethical conduct or abuse of position are occurring. The position of the researcher in this study is further illustrated in section 4.14.

In any ethnographic study, the researcher has a complex position with regards to the setting and also in relation to the participants in the group under study. There are advantages and disadvantages to both approaches, whether an insider or an outsider to the research setting, and these will now be considered.

The traditional ethnographic position of being an outsider is a privileged position, and can support objectivity, as the ethnographic researcher does not have any prior knowledge or status in the group under study to affect their position or their discovery and subsequent interpretation of the findings (Hammersley and Atkinson 2007). Concerns are held for insider ethnographers, who due to their experience and emotions, can prevent the researcher from being distant and detached from the data collected and therefore affect the objectivity of the research (Asselin 2003).

Insiders become absorbed in the setting and some argue that they cannot see the larger picture or perform analysis, however, concerns over the time which is required

to be spent in the setting to gain access by an outsider support the use of this method with an insider researcher (O'Reilly 2009). Particularly in healthcare research, insider ethnography has a value, as it can allow for greater understanding of healthcare practice and it continues to develop to allow the understanding and the generation of knowledge on some specific healthcare issues and behaviours.

The insider position can be negatively viewed in terms of trustworthiness, as the researcher is too familiar to achieve the required curiosity. However, conducting research within a setting in which the researcher is familiar has advantages. One of these is the ease of access by being known to the institution and setting, allowing quicker access to participants and gatekeepers due to this existing role and known position.

Being known also can support the data collection as rapport can be further developed. Rapport will have already existed with a number of patient and staff participants, therefore time was saved, as the researcher was already known to them and this rapport did not require to be established with all participants. Also by knowing the setting, it has been identified that researchers will be less disorientated than if they had entered an unknown culture (Savage 1995) to conduct their research.

Borbasi et al (2005) in their reviewing literature on nurses undertaking fieldwork suggest that nurses are in a strong position to carry out observational research in settings with which they are familiar, due to their professional experience and background.

Concerns about the insider researcher can arise if the researcher believes they already understand the setting and culture under study. Having established assumptions about an area can limit the researcher's ability to probe into aspects for deeper or hidden meanings due to their prior understanding. As part of conducting this ethnographic insider piece of research, the researcher constantly considered their position and existing perspectives through reflexive practices and using the field diary to note elements for consideration as suggested by other literature, particularly as a nurse researcher (Asselin 2003).

Despite either position, the ethnographic researcher must strive to make the strange familiar and the familiar strange (O'Reilly 2012). They must constantly question, immerse and distance themselves to produce the insights important in ethnographic research. To support this constant move from immersion and distance within the known and familiar setting, the researcher used reflexivity as a tool. Reflexivity is an important concept and must be utilised by a researcher in both insider and outsider ethnography (Davies 2008, Hammersley and Atkinson 2007, Atkinson et al 2001).

Reflexivity allows for the research design, data collection and subsequent analysis and results to be viewed as trustworthy by the researcher and the subsequent audience. Reflexivity is a concept that is discussed further in 4.15.

4.8 Research Process

Whilst ethnography is a research design used to investigate the social world and the people who make it, different methods can be used as part of the data collection process, using the unique position of the researcher in the field.

The main method of data collection as part of this ethnographic approach was participant observations, with fieldnotes and photographs taken by the researcher, and the informal questioning of the participants as part of the observations and fieldwork. Semi-structured interviews were also conducted by the researcher, on a smaller, purposive sample.

The researcher was in the field for nine months, with the first month in the field having a focus on providing information on the research and beginning to obtain the participants' written consents. No data was collected or fieldwork conducted at this point. The next 8 months comprised of fieldwork allowed for the combining of data collection and some data analysis, but also the continuing consent processes, due to changes in the participant groups.

4.9 The Setting – entering and drawing up the lines of the field

Ethnography requires to have a 'field' which is under study or contains the participants under study. The researcher requires to negotiate entrance to the setting

or field, usually through a 'gatekeeper', who provides permission and facilitates access to the field site and potential participants. In this research, the main gatekeeper was the Charge nurse. NHS ethical permissions and the senior service managers' permissions were also required for the research to be conducted within this setting.

Haemodialysis units are specialised areas with a regular population, who are easily accessible through their regular attendance to the setting, allowing ethnography to be an appropriate methodology to use for this research.

Importantly, within ethnography, the lines or boundaries of the field site require to be defined. In this research, this was where the care takes place, with a main focus on this part of the unit, not the other parts e.g. waiting room etc. However, this was also due to the ethical restraints of using this area when patients were present.

The setting for the study was a large regional haemodialysis unit, situated in a large teaching hospital in the United Kingdom. The main unit has approximately 120 patients regularly receiving haemodialysis treatment three times a week on this particular site. The unit is also linked to three smaller satellite units.

The haemodialysis unit was made up of five rooms, each with either seven or eight haemodialysis spaces. There was also a waiting area, three offices and a seminar room adjacent to the main clinical area, which was utilised for interviews of staff, and patients who wished to be interviewed when not receiving haemodialysis.

Access was given to the researcher from the charge nurse of the unit and the service manager within the NHS site responsible for this particular setting.

The researcher in this particular research was an insider researcher, having held and remaining to hold a small clinical position as a registered nurse in the unit. During the fieldwork, the member of staff worked within the unit in a clinical capacity two days a month, although two days in the month the researcher worked in the wider renal area, and not directly in the research setting.

The researcher entered the field as a researcher most days for the first few months of the data collection. This allowed the researcher to be there in the position of the researcher to provide information to staff and patients, keep track of recruitment and changes in patient or staff status.

4.10 Data Collection

4.10.1 Participant Observation

Observation is a crucial part and key method within ethnography. This particular method of data collection allows the researcher to witness events in their natural environment, to see what is actually going on, rather than what individuals might think they do or do not do. Observations allow for the ‘interweaving of looking, listening, and asking’ (Lofland 1971 p109), linking what the researcher has seen and heard (Roper and Shapira 2000).

Observations allowed for information to be gathered about different things including people and behaviours, verbal and non-verbal communication, activities and the environment in the haemodialysis unit. The observations focused around the caring practices and interactions that occurred in the haemodialysis unit, which allowed a holistic view to be gained from the research. Although observation is not limited to this, it can include anything which the researcher witnesses during the observation sessions. Observation does also demand the researcher’s highly focused concentration to gain information through this method, so the researcher required to focus during this element of the research on what is happening around them (Salmon 2015).

Observation can vary depending on the researcher or observer’s position in the field and their engagement with that field and occupants. This position can range from being a complete observer, where the researcher only observes and does not participate, to the opposite, where the observer is purely participating. Gold (1958) suggests there is a middle position which shares both of these values- either participant as observer and observer as participant.

Within this ethnographic research, the researcher’s position was in this middle ground where the researcher would be able to participate and observe during the

period of observations. Brewer (2000 p61) suggests that the observations in this research could be classed as 'pure observant participation' by using the researcher's existing role within a familiar setting.

Participant observation is one way in which observation is described by some as the centrepiece of ethnographic research (Murchison 2010, Atkinson et al 2011).

Participant observation is where the researcher is a participant in the setting under study. The participant observer role, filled by the researcher as the data collection instrument, allows the immersion within the group and setting. They are able to participate within the setting, whilst observing and documenting the events and behaviours which occur naturally. Key to the researcher being able to participate in participant observation, they must become part of the group or culture, gaining trust and therefore being able to access more observational data (Brewer 2000). In this research, due to the researcher's known background and established position within the field, this access and rapport with participants was anticipated to be easier.

Access into the group and the consenting process was mainly achieved within the first month of being in the field and was facilitated through the prior role and knowledge of the area and contact prior to starting the research.

At some points during the research, during observation situations, the researcher was in the field in a purely observational role, watching and listening to the participants and taking notes in the form of fieldnotes. Other times, the researcher was more prominent, and was able to engage with the staff and patients within the setting during the fieldwork times. O'Reilly (2009, 2000) writes of the balance between being an observer and participant shifting within her research dependant on the situation. The flexibility of the researcher to adapt their role and extent of participation is important when conducting ethnographic research, particularly in healthcare contexts, where participation might be inappropriate or insensitive.

The observations conducted in this research followed the approach detailed by Spradley (1980), beginning with descriptive general observations, which will then become more focused and selective as the research progresses.

Descriptive observations were made at the beginning of the study, or exploratory stage, allowing the researcher to become aware of the variety of events which occur within the haemodialysis unit. The descriptive observations allowed the researcher to become aware of the variety of events that occur. These descriptive general observation episodes allowed the researcher to start looking at the area as a researcher, and not only as a member of staff from the area.

Observations then became more focused and systematic, where some things observed could now be ignored and others were looked at more closely. An example of this was focusing on what nurses 'do' within the setting, not only the interactions with patients, but also the other aspects of patient and staff activities within the haemodialysis unit.

Finally, there were selective observations. The observations here were detailed and at this point and considered the setting, participant, frequency and duration, process and outcomes of the activities on or around patient care.

Questions to guide all the observations were used, a system advocated by LeCompt et al (1997). This strategy forms the use of the 'who', 'what', 'where', 'when' and 'why' questions, which form part of the fieldnotes on the observations (LeCompt et al 1997). The naturally occurring conversations within the unit between individuals under observation were observed and recorded as fieldnotes.

This type of observation is appropriate in this study; as the role of the researcher is made explicit prior to and during the data collection periods, the observations are not covert. Participant observation can also allow for the informal questioning to explore things with participants as they happen. If the researcher had a purely observational role, the different elements witnessed could not be followed up directly as part of the data collection.

Observations were conducted in five to six hour blocks, covering one shift of patients. This covered all the patients on their arrival into the specific dialysis room, their time on the machine and also when the treatment was finished and the patients

would leave the room. This also covered the registered nursing and healthcare support workers within this time and their different actions and behaviours.

This format allowed the research questions to be answered and understand the concept of direct patient care in this particular context. There was not a pre-planned target for hours of observations to complete, due to the uncertainty of participant numbers and the ethical restrictions on requiring consent from all patient and staff participants in the particular room under observation.

Prior to the commencement of the research, it was planned that one observation session could be conducted a week. Observation sessions became dependent on patient participant consent and staff participant consent and availability.

Overall 20 full observation sessions occurred, with three shorter sessions occurring, due to consent issues requiring the observations to stop. One session had to be cut short due to a ward patient arriving in the room for treatment who was unable to be part of the research.

As patient participants would be in the unit and cross over with two groups of staff, two sessions halted when the second shift of staff arrived, due to the staff who were working in that room not providing consent for the project. Despite this limitation in the data collection, the volume of data collected should not have been affected due to these slightly shorter sessions.

Overall, 127 hours of participant observations occurred during the research. The research had a prescribed end date as approved by the ethical committee, so no further research was able to be conducted after this date, causing data collection to cease at that point. Due to the 127 hours of observations, it was felt enough data had been collected and that the end date did not negatively affect the research process.

Fieldnotes

Fieldnotes are the documentation of all the observations and informal questioning and conversations from the fieldwork, helping describe the researcher's whole -of - body experience (Madden 2010). The fieldnotes are a 'thick description' of the

fieldwork, as ethnographic data and interpretation is linked to setting, place and time (Mulhall 2003, Geertz 1973). Thick description is further considered in 4.13.3.

Fieldnotes are a way of allowing the researcher to have written down all the information they think is relevant to the research (O'Reilly 2012). They provide a descriptive account of people, scenes and dialogue alongside the personal experiences and reactions of the researcher (Atkinson et al 2011).

Fieldnotes are a way of formally keeping a record of what has been observed in the research site. Fieldnotes began as soon as the research experience begins, documenting observations, conversations, feelings and interpretations. This raw data was then transcribed and used for analysis. The fieldnotes also allowed the researcher's thoughts to be collected alongside the research process. By writing things down, the researcher's memory was not solely relied on, and this allowed for a large volume of written and transcribed data be collected. Items which were documented where who was interviewed, who refused, different responses to the research and comments made during the consenting process. Events that occurred or events recalled, for example when the staff informed the researcher that a patient had died on another shift, were noted in case it had relevance to subsequent data collected or analysis and to establish the context of the research.

A problem with writing extensive fieldnotes is that actions and behaviours may be missed, as the researcher would be too busy documenting them. Fieldnotes will be both partial and complete, depending on the situation. Fieldnotes were written anonymously into a notebook and then transcribed and stored securely on a computer within the University in line with the ethical approval. The fieldnotes were transcribed as soon as possible after leaving the observation or field, within 24 hours of the observation period, to ensure that data is recorded correctly with things still fresh in the memory of the researcher.

The detailed description forming part of the researcher's fieldnotes can allow the reader to see what is there, and the description can then support the argument or theory or interpretation. The fieldnotes provide a reference point, and can show the data to allow for the interpretation to be regarded as trustworthy.

The fieldnotes also included aspects of the researcher's thoughts. These are sometimes detailed separately in a field diary, however the researcher detailed within the fieldnotes their flashes of insight during the fieldwork, which was an aspect of the researcher being able to stand back as part of their reflexive practice and further analysis of the data (O'Reilly 2012).

Informal Questioning

Informal questioning within the participant observations allowed the beliefs and views to be gained by participants immediately after or around an activity.

Explanations can be gained on smaller activities to gain feedback when a situation is fresh in the respondent's mind. These informal interviews are merely natural conversations, different to a semi-structured interview, where certain things will be discussed in a formal way. The participant observer role allows for the use of informal questioning of the participants as part of the observation, following up on things seen at the time (O'Reilly 2012).

Listening to the informants is key in ethnography, gaining explicit knowledge by asking questions and talking directly to participants to gain their insider's point of view.

Photographs

Photographs have been well used within ethnographic research. Photographs have been used for illustrative purposes, to show aspects of the group under study and can be linked to the data collected. Photographs can also help establish the researcher's authentic presence in the field and demonstrate their presence in the research setting (Davies 2008). Collier (1967) has argued that the use of a camera within ethnography and anthropological research can allow more to be seen, and that what is seen can be more accurate. He argues that the ethnographer's camera can be an extension to the researcher's senses, allowing an entire scene to be captured rather than the particular unit on which the focus is placed.

Photographs are also a product of the researcher, selected to reflect a particular view or vision. When using visual methods, researchers must be sensitive to their use, and

be aware of the potential use and understanding of photography within the setting, society or culture (Pink 2014).

Photographs were taken during the fieldwork by the researcher to assist in the understanding of the research aim/question and to provide visual aids to illustrate different situations. Photographs are restricted to time and space; a photograph does not record what the researcher can see and hear, it just displays a limited selection of what could be observed from the same position. Davies (2008) describes a photograph as displaying 'a slice of time' (p133), and views them critically, as they can be staged and altered before they are presented as part of the research.

The researcher's own digital camera was used to take photographs during the observation sessions. The photographs were taken and then all faces were blurred, to ensure that the participants were not identifiable, per the NHS Ethical guidelines and also in line with local NHS policies. Adobe Photoshop 2014 software was used to blur the identifiable features of participants on the photographs.

Overall, 207 photographs were taken, with 188 photographs being used by the researcher to illustrate the wider dialysis area. Thumbnail images of the 188 photographs are presented in Appendix 11. 19 photographs were deleted due to being poor quality images. Photographs were taken and notes made in the fieldnotes numbering each photo and detailing what it was showing or happening at that point, to aid the researcher when reviewing the photographs after the observation session.

Photographs did not leave the hospital buildings, in line with the ethical permission. The photos were uploaded to a university computer following the observation session, then deleted from the camera, so they only existed on a secure server. The photographs were then altered so as the identifiable features of faces would be obscured so that participants were not directly identifiable.

Recruitment and Sampling for observations and photographs

The initial approach to all parties was through a letter from the Charge Nurse in the haemodialysis unit (see appendix 3, 4 and 5 for flow charts on patient recruitment and staff recruitment). All nursing staff and regular haemodialysis patients within

the unit received information about the study and the opportunity to participate in the research.

The Charge Nurse approached each patient with an introductory letter, a patient information sheet and an Opt in/Opt out slip. If the potential patient participant was interested in participating in the research, they were required to complete the opt in/out slip. The completed slip was then handed to a member of staff, who put this in a box in the staff room for the researcher. If the patient was not interested in participating in the research, they were also required to complete the opt in/out slip to that effect. This was then also placed in the box by a staff member for the researcher to collect.

Depending on the responses received, the researcher could then approach the patient to discuss the study and then potentially look to recruit and seek consent for the observation aspect and photographic aspect of the research.

If a patient did not complete the opt-in/out slip, then the patient was not approached by the researcher or provided with further information on the research.

All the patient participants who completed the initial opt-in portion of the slip subsequently provided consent for the study when approached by the researcher with further information. These patient participants were then approached on their next dialysis session, at least 48 hours after this follow up approach from the researcher, to provide written informed consent at this point.

Some patients who opted out did write on the form why they were opting out whilst other patients did approach the researcher, on both days during fieldwork and normal working days to explain why they did not want to participate. When a haemodialysis room contained both regular patients who opted in and then consented, and also regular patients who had opted out and therefore not provided consent, the usual room and configuration of patients here meant that no research was able to occur. In line with ethical guidelines, these consented patients were unable to be used for the observation sessions if the opted-out patients were present. The opt-in patients were still approached for consent, so they could be considered to provide an

interview, or should rooms change and patients move shift or room, then they may have been able to participate at a future point in the field work.

This happened on one occasion during the fieldwork, where a space became available in a room which had already achieved all patients being consented, and the patient who moved into this space was a patient who had already consented, but was originally in another room. The move was unrelated to the research and led by the charge nurse due to patient need. The researcher required to keep track of all the patients who had consented and the level of consent provided, so as to comply with the ethical guidelines.

As the Charge Nurse was well positioned to know the patients, if a patient was identified as an adult without capacity, an introductory letter, information sheet for welfare guardians and opt-in/out slip was sent home with the patient and again if this did not come back with the patient or the welfare guardian did not contact the researcher, then no further approach was made, in line with the NHS Ethics Committee Guidance.

All nursing staff in the unit were approached by the Charge Nurse with an information sheet on the study as an invitation to take part. The researcher spent time in the field in the role of researcher over the first month of consenting, and then the proceeding eight months of fieldwork to answer questions about the research, and recruit staff who expressed interest in participating in the project.

The main criteria for participants to be invited to be involved in the study was to be either a regular haemodialysis patient within the unit or a registered nurse or healthcare support worker within the unit. Each specific dialysis room of regular patients and staff were given the opportunity to be included in the study, so as to include as many patients, staff and situations as possible. The youngest patient who participated in the fieldwork and research was 22 and oldest was 81. There were patients who were outside this age bracket who receive haemodialysis, but they did not consent to participate in the study.

Recruitment for participants is detailed in Table 4 and flowcharts are available in Appendices 4, 5 and 6 of this process. Ethical permission was granted by the NHS Research Ethics Committee (REC A) to approach patients who were adults with incapacity to consent via approach to their welfare guardian or relative (see Flowchart in Appendix 4). Whilst no patients were recruited who were part of this category, five patients did fall into this category. This meant that the rooms where these patients received their haemodialysis could not be part of the observation element of the study, as appropriate consent was not provided.

As dictated by NHS ethical guidelines, participants were able to consent to be in the study in three ways. Participants could be in only the observational aspect of the study, both the observations and the photographs, or both of these elements also in addition to a semi-structured audio recorded interview.

Table 4: Overall Recruitment Numbers

	Participant Numbers for Observations	Participant Numbers for Photographs	Participant Numbers for Interviews
Patient participants	55	55	12
Registered Nurses	42	39	12
Clinical Support workers	5	5	3

Other members of staff may be working within the unit at different times e.g. medical staff, dieticians, social workers, but as these staff groups are not particularly involved in the idea of direct patient care, they are not relevant to the research question. Patients or both groups of nursing staff may mention these groups within the interviews, but observing them is not relevant to this study and the research questions.

In rooms where all patients and staff had consented for observations, but not all had provided consent for the photographs, the researcher had to keep track of the staff who had not provided consent for this aspect, so that they were not captured in photographs.

One consideration in the recruitment process was the potential change in participants, due to the research being over an eight-month period and patients may no longer attend the unit; either due to a change in circumstances from being transplanted or no longer attending for treatment, due to ill health or withdrawal from haemodialysis. When this happened, the space may have become filled with another patient and once they were established as a permanent haemodialysis patient, the Charge Nurse would be required to approach with an introductory letter, information sheet and opt in/out slip as per the recruitment flowchart.

It was the role of the researcher to ensure that new patients and new staff to the area would be identified to the charge nurse and the approach would then be made.

Within the NHS ethical approval, for an observation to take place within the room, the whole room of patients and nursing staff working there on that shift required to have consented to be observed in the research study. If, within a room, a patient had not given informed consent or there was a patient who was not eligible to be recruited e.g. a prisoner or was not a permanent patient, i.e. was an acute case and not established on treatment, then that particular session on that day could not be observed.

Key to the observation element of the research is trying to observe as many patients and staff as possible in different situations within the unit, thus trying to minimise missing different and important observation situations. Observations did capture a variety of different staff in various senior nursing team positions as well as the more junior staff, but this was dictated by who was working during the observation periods also dependent on patient consent and observation opportunities.

Despite having written informed consent from all the patients and staff in the room prior to the observation being conducted, during the shift prior to the planned

observation, patients were informed that observation would be taking place next time, and asked if they had concerns or changes in consent at this point. At the start of the observation session, opportunities were also given to patients and staff, should they no longer wish to participate. A specific recruitment notebook was kept by the researcher to manage consent processes and regular patient spaces.

4.10.2 Semi-structured interviews

Gathering data through an interview can be an important aspect of ethnography. An interview can allow for the gathering of a narrative to provide knowledge and understanding to the research question. Interviews describe, explain and explore issues from the perspective of the participant (Rubin and Rubin 2012). They require a verbal exchange between the participant and the researcher or interviewer. The researcher or interviewer wants the participant to talk without interruptions, as they facilitate the interview by probing and listening.

Considering the type of interview to be conducted depends on the purpose of the interview. Structured interviews can be described as a 'verbal questionnaire' (Newell and Burnard 2006 p60). There is a series of questions which are answered by the interviewee. They stick rigidly to the interview schedule and it does not permit an exploration of responses. In contrast, unstructured interviews will all begin in the same place with the same question, but the dialogue can move from topic to topic as the interview develops and no exact pathway is followed. Unstructured interviews are difficult to manage as they are guided by the participant's responses and do not end in the same place (Rubin and Rubin 2012). This form of interview may lose focus, and no longer be related to the research question (Rubin and Rubin 2012).

A variation on both of these interview types is the semi-structured interview, which was chosen for use in this research study. This is where the interviewer has some topics, questions and lines of enquiry prepared, but they also can also prompt the interviewee to reveal more in their responses. The interviewer can also change the order of their questions or topics depending on how the interview progresses. The semi-structured approach allows the researcher to focus on particular topics but also to gain in depth information.

The questions were contained in a topic guide (Appendix 10), which helped the researcher to collect similar types of data from the participants. The researcher is able to be in control of the semi-structured interview, but despite this and the use of a topic guide not every interview was the same. Using a topic guide allowed for the researcher to ask these predetermined questions, as in a structured interview, but also allows the exploration of the responses using probes. Probes helped in seeking clarification and more answers, and can be made up of exploratory questions following up on certain points made by the participant (Rubin and Rubin 2012).

To capture the data presented during the interviews, a digital voice recorder was used. This allowed the researcher to listen to the participant's narrative at the time and also after the interview, facilitating transcription and analysis. This method of recording the data preserves the exact words in the interview so nothing is forgotten, and allows the researcher to be able to focus on what the participant says. Notes were also taken during or after the interview to aid the researcher interviewer in the research and analysis process. The files of the interviews were uploaded onto a secure network at the university and then deleted from the voice recorder. All data was anonymised when transcribed by the researcher, to maintain the anonymity of the participants. Pseudonyms have been used when presenting the data in this thesis.

Single cubicles within the haemodialysis unit were utilised for patient participant interviews, should the patients wish to be interviewed when on haemodialysis. With permission from the charge nurse, patients could be allocated to these specific haemodialysis spaces instead of their normal space, as long as the spaces were not required for other purposes.

Unfortunately, during the fieldwork, the planned patient participant interviews sometimes required to be postponed, rescheduled and some were unable to be undertaken as these cubicles were required for clinical need rather than research interviews.

Recruitment and Sampling for Semi-Structured Interviews

Selecting the participants for the semi-structured interviews occurred once observations had begun and was dependent on the participants who had consented

for the observation and photographic elements of the research. If participants had not consented for both these aspects, they could not be approached to be interviewed. Flowcharts regarding the process of participant recruitment for the interviews are available in Appendices 7 and 8.

The original aim was for 30 formal semi-structured interviews to be conducted. The potential participants for the semi-structured interviews were identified from the observations and fieldwork. These participants are identified as key informants, as individuals who were either highly knowledgeable about the setting or contrasting the other key informants. This sampling strategy is a combination of a convenience and purposive sampling, with an attempt at maximum variation within the key informant group. By starting the observations before the recruitment for the interviews, their level of knowledge and willingness to participate was gauged prior to considering approaching them regarding participation in the interview aspect of the research.

Some of the samples of staff and patients selected for the interviews were purposive, to help ensure that the key informant group was close to being representative of the whole population in the project. It was planned to recruit two or three patients to be the key informants from each shift, using different rooms, male and female, older and young and taking into consideration the length of time in which they had required haemodialysis treatment.

The researcher had hoped to identify 15 patients and 15 members of nursing staff from the observations or consenting process as key informants and participate in an interview, however this was not fully achieved.

Within the nursing staff participant group, 16 members of nursing staff were identified, with 15 consenting and participating in an interview. Three of these participants were healthcare support workers, to ensure representation from both groups of nursing staff in the interviews. The nursing staff recruited for the interviews were of varying ages, gender and length of service within the unit and renal areas, to ensure that a range of voices was represented in the research.

Identifying 15 key informants from the patient participants, who had consented for the observation and photograph elements of the study, allowed a variety of participants to be approached for interviews, who had not been able to be observed, due to other people not providing consent.

By using patients who attend on different days and at different times, the full range of patients were included in the research study, in order to capture different patient experiences across the days and times of treatment within the sample.

Patient participant recruitment numbers for the completed interviews was not achieved, despite having over the 15 participants willing to participate in an interview. Within the haemodialysis unit, the two cubicles to be used for haemodialysis patients when receiving their haemodialysis for interview could not be accessed, due to patient needs. 12 patient interviews were conducted, however there were three other patients identified who had been interested in participating in an interview. Unfortunately, these were unable to be conducted, despite the patients' willingness to participate.

All the participant interviews lasted between 35 minutes and 90 minutes and were audio recorded using a voice recorder and transcribed by the researcher as close to the interview taking place as possible – between 24 to 48 hours following the interview. The 12 patients who participated in a semi-structured interview whilst on haemodialysis included seven female and five male patients who had attended for haemodialysis for varying amounts of time and had different backgrounds pre-haemodialysis (Table 5).

The participants were also spread between the different shift patterns³, either being a Monday, Wednesday, Friday attender or a Tuesday, Thursday, Saturday attender and the pseudonyms are shown in Table 5. Seven of the patient participants received their regular haemodialysis treatment in the morning shift, two normally attended in

³ Shift patterns: patients in this particular unit have a space at the same time three times a week when they would usually attend for haemodialysis. The treatment times were either a.m. (0800-1330), p.m. (1330-1830) and twilight (1830-0030). Sometimes the patient's treatment may run on into the next shift time if there have been complications. Patients usually receive treatment on three days each week, this is either Monday, Wednesday and Friday or Tuesday, Thursday and Saturday.

the afternoon and three in the evening on a twilight shift. The researcher had hoped to get a more even split between the shifts, but this sample still gave a variety of shifts and perspectives from patients about care in the haemodialysis unit.

Table 5: Patient Participants- Semi-Structured Interviews

<i>Female patient pseudonyms (regular shift for treatment)</i>	<i>Male patient pseudonyms (regular shift for treatment)</i>
<i>Rita (p.m.)</i>	<i>Jerry (a.m.)</i>
<i>Betty (a.m.)</i>	<i>Edward (a.m.)</i>
<i>Sandra (a.m.)</i>	<i>Donald (p.m.)</i>
<i>Barbara (a.m.)</i>	<i>Phil (a.m.)</i>
<i>Martha (t/l)</i>	<i>Bob (t/l)</i>
<i>Judy (t/t)</i>	
<i>Emma (a.m.)</i>	

There were 12 registered nurses interviewed by the researcher, one male and 11 females. This is representative of the high ratio of female registered nurses to male registered nurses in the haemodialysis unit. Within this sample of registered nurses, there were various levels of senior and junior staff, including band 5 nurses and some promoted band 6 nurses who remained involved in patient care. Two male healthcare support workers and one female support worker were interviewed. This was to ensure a mix of staff who had worked in the unit for varying lengths of time (Table 6 and 7).

Tables 5, 6 and 7 show the pseudonyms used within this thesis when considering the presented interview data.

Table 6: Registered Nurse Participant Pseudonyms- Semi-Structured Interviews

<i>Charlie</i>	<i>Lee</i>	<i>Marty</i>
<i>Dani</i>	<i>Charlene</i>	<i>Angie</i>
<i>Pat</i>	<i>Holly</i>	<i>Julie</i>
<i>Jan</i>	<i>Tina</i>	<i>Darcy</i>

Table 7: Healthcare Support Worker Participants- Semi-Structured Interviews

<i>Jo</i>	<i>Billie</i>	<i>Lewis</i>
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The researcher had hoped to get three male registered nurses for interview but only recruited one for the interviews. The researcher also hoped for two male and two female clinical support workers, however only one female and two male participants were recruited in this group. Despite this, 15 interviews with staff were achieved and data gained from both male and female members of staff as part of the research study.

4.11 Ethical standards guiding this study

A favourable ethical approval was gained from the NHS Research Ethics Committee (REC A) in November 2013 following the REC A meeting in September 2013. Following the meeting clarifications were requested by the committee concerning the initial approach to patients (see Appendices 12 and 13 for letters).

Recommendations were made by the committee, as there were concerns raised on the proposed arrangements for approaching patients and allowing them the opportunity to participate or decline participation. Appropriate changes were made to the study protocol, where the Charge Nurse would make the initial approach and invite patient participants with a letter (Appendix 15) and an opt in/out letter slip (Appendix 14). This opt in/opt out slip required to be completed by the patient or family member and

returned to the nursing staff in the unit. If completed as 'opt in', this would then allow for the researcher to approach and offer more information to the potential participants. The Charge Nurse went to each patient when they were on dialysis to hand over this opt in/out slip, initially over the course of 3 weeks, and the researcher also identified when new patients required to be approached and would prompt the charge nurse to pass on the information and the opt in/ out slip.

The opt in/out slip mechanism was in order to ensure that patients did not feel coerced in any way by the researcher, since the researcher also was employed to deliver direct care in the area of data collection. Patients may have felt obliged to take part if approached by the researcher, and may have been unclear about the role of the researcher in this instance. Haemodialysis treatment and care would not be affected through participation or non-participation in the research study.

Before any data was collected in the unit, a letter to all current staff was issued by the researcher, to ensure that all were aware of the planned research and what would be taking place in the area over the nine-month fieldwork period (Appendix 16).

During the fieldwork period, this information letter was then given out to new or visiting nursing staff to inform them of the project that was taking place. This opportunity then led to the information and consent forms being issued to staff if they have wanted more information or if they wanted to consider participating.

All patients and staff who attend the haemodialysis unit were required to give written informed consent to be observed and be part of the research. The key informants for the interviews were given a consent form to read and sign before the interviews were conducted, and it was made clear at the start of the interviews that it was possible to terminate the interview at any point with no questions asked, without treatment or care being affected (See Appendices 17 - 21 for all approved information sheets and consent forms).

Participants who were unable to communicate in English and provide consent due to language barriers, were approached with the opt in/out form and information sheets translated into two other languages- Russian and Cantonese. Despite this, these patients did not provide consent, but including them in the population and providing

them with the option to be included in the research was viewed to be important to the study as they do receive care in the haemodialysis unit.

During the entire study, and particularly during the observations, the researcher's role was known and was made as explicit as possible. This helped to ensure the study did not use any covert observation techniques, as it was not intended to be part of this study and is considered both unethical and inappropriate.

The interview consent forms had information on support services, as the interview could have revealed or highlighted an issue that the patient or staff member would like to further pursue. The interview data was anonymous once transcribed, in order to preserve the participant's anonymity. The researcher also had a responsibility to protect the patient, and knew they must intervene should safety be compromised, even if this affected the study.

For the patient participant interviews, to allow confidentiality, interviews took place in a cubicle where the door was closed for privacy from the other patients and staff. Whilst the researcher was not there in a nursing capacity, staff outside the room would be able to be alerted quickly by the researcher should they be required, due to the researcher's prior knowledge and insider status.

If nursing staff did need access to the patient participant during the interview, the researcher paused the interview and voice recorder until the staff had left the room and then restarted the recorder and continued the interview. This was to allow the confidentiality of the patient and also to preserve the right for the staff member to not be recorded inadvertently. The staff on shift were also informed prior to the commencement of the interview that this would be taking place, so the staff could take this into consideration when planning and carrying out their duties. This only happened on one occasion, where the staff offered the patient a cup of tea.

All the data collected from the observations, fieldnotes, photographs and interviews was stored securely, in accordance with local NHS guidelines and the university data protection regulations and procedures. The photographs were transferred onto the University computer server before they left the NHS building, then deleted off the

camera prior to the camera leaving the building. The photographs were anonymised once on university computers and then the originals were deleted so that no participant could be easily identified. Anonymised data was shared with the two research supervisors to aid data collection and analysis.

There was no exploitation of the participants in the conduct or recruitment of the research. The researcher ensured no harm or discomfort was caused to the patients by taking part in the research. There was also no likely benefit to the participants by taking part in the research.

All the participants were treated with respect, and the non-participants were not treated differently due to their lack of participation in the project when the researcher was conducting their job as a nurse. The researcher and the research had due regard for the welfare, beliefs, perceptions, customs and cultures both of the patient and staff participants. The privacy, confidentiality and cultural sensitivities of participants were respected by the researcher, as nothing was discussed from the research process with anyone related to the project until the project was finished.

4.11.1 Ethical Permission to include Adults without capacity

As part of the ethical permission granted for this research, adults with incapacity could be included, if appropriate consent had been obtained by their welfare guardian. Within the ethical committee meeting, the researcher argued that the study would allow the types and forms of care which occur in the haemodialysis unit which is received by adults who lack capacity to be understood.

The use of ethnography and observations would allow the description and explanation of direct patient care as a phenomenon within nursing practice. This patient group and their needs within the context of the whole unit could be identified, and knowledge concerning the direct patient care they receive could subsequently be improved. By improving knowledge and understanding on the types and forms of direct care in haemodialysis, an improvement in the care patients receive and the needs they have can be addressed so they can be adequately met by nursing staff. It would also benefit the adults who lack capacity who receive haemodialysis, as it will allow for the needs they exhibit and the care provided to them to be observed, which

can allow for care needs to be met in practice. No patients who were deemed to be without capacity had consent provided on their behalf from a welfare guardian. This element within the research did mean that if patients had a change in their mental capacity, there was still the potential for them to continue with the research. If patients who were deemed without capacity subsequently became able to consent, they would then be approached to self-consent to participation. If a patient also changed mental state and was, during the research, deemed to be an adult with incapacity, the participant would still be eligible to participate in the observations, should consent be gained from the family member or welfare guardian.

In the unlikely event of any patient being distressed, whether this was an adult without capacity or someone with capacity, the researcher would cease data collection should it not be appropriate in this situation, potentially causing undue stress on the participants.

4.11.2 Researcher Duty of Care

As part of the research protocol and ethical practice of the researcher, witnessing unsafe and inappropriate practice and a course of action was written into the research design. The duty of care from the researcher as a registered nurse and experienced dialysis nurse was stipulated in the information sheets for staff and patient participants. These stated that the researcher has responsibilities to follow up or intervene in care should any untoward incident or emergency situation arise during their presence in the unit. The researcher's duty of care to protect patients would be upheld and incidents would be reported to the Charge Nurse. This again was explicitly part of the ethical approval process.

During discussions with nursing staff about their participation, some asked about what the researcher would be looking at, and what they would be doing when watching staff. Time was taken to explain the researcher's position, to protect the patients, but they were not specifically focusing on particular staff and their practice. No incidents required to be reported to the Charge Nurse.

Due to the researcher's participant observation position, emergency situations could be acted upon in their research role. One situation did arise where the researcher did

require to step into a participant position within their professional role and support a member of staff. This incident is further discussed as part of the reflexivity section 4.15 and required the researcher to assist in intervening by providing equipment to a staff member caring for a patient, in order to preserve patient safety in this situation.

4.11.3 Refusing Consent

Patients and staff within the area did decline to participate at initial the opt in/out stage. This was not pursued with any of the non-participating staff or patients on either a research day or a working day, as this would have been inappropriate. One patient did volunteer to the researcher when they were passing through the unit on a recruitment day that she was sorry she wasn't going to be involved, as she had a lot going on with her life and was regularly feeling unwell on dialysis. This response from the patient was not sought by the researcher and was offered without any probing from the researcher on this topic.

During the course of being in the field, the researcher encountered varied responses to the research and their presence in the unit on both research days and working days.

Several of those, both nursing staff and patients, who declined to take part remained very interested in the conduct and findings of the study. They would ask the researcher about the study whilst it was ongoing and after its completion. The researcher did not dismiss these interests and did tell anyone who asked that things were progressing well

Some staff refused to take part in the research, having been provided with the information. The researcher again did not ask why, as this could easily have been seen as coercion to colleagues and potential participants.

4.12 Data Analysis

Data from interviews, observational fieldnotes and informal questions all formed the written elements of data provided for this research.

Qualitative data analysis is viewed as a complex and mysterious aspect of a research project (Thorne 2000). The analytical approach used for this research was thematic analysis and occurred during the fieldwork and after the fieldwork was completed.

Analysis within ethnography is considered inductive by nature. Knowledge, ideas and theories are constructed from the data collected, however analysis and data collection both happen together when conducting an ethnographic project, rather than as linear or separate distinct processes (Figure 8, Creswell 2013). Analysis takes time, with the researcher committing to the accurate organisation and sorting of the data into these ideas or themes.

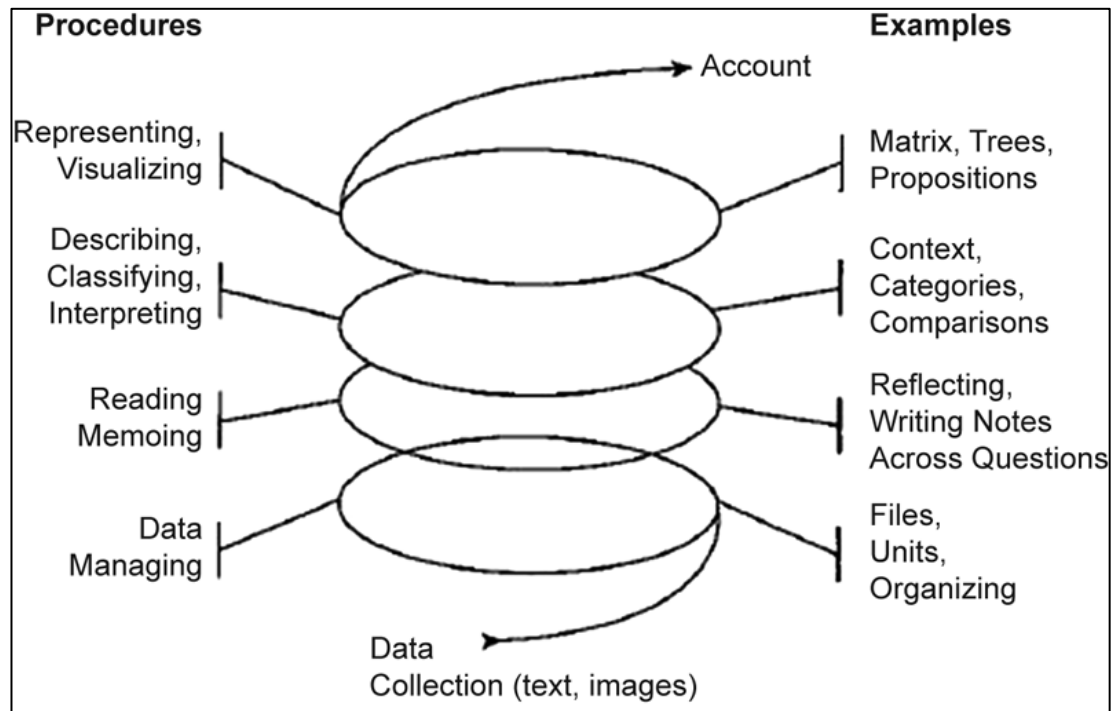


Figure 8: Data Analysis Spiral (Creswell 2013 p183)

4.12.1 Thematic Analysis

Thematic analysis is regarded as a flexible approach (Braun and Clark 2006); more flexible than content analysis or grounded theory approach. This form of analysis is ‘independent of theory and epistemology’ (Braun and Clark 2006 p78), unlike other approaches to analysis which are tied to different theoretical positions and have limited variability because of this (Braun and Clark 2006).

This type of qualitative data analysis starts with identifying, analysing and reporting patterns or themes found within the data. It minimally organises and describes the

data set in rich and descriptive detail and then allows for the interpretation of various aspects of the research topic (Braun and Clarke 2006).

Thematic analysis was used for the written materials in the research. It is a more inductive form of qualitative analysis, as the themes are not decided prior to the analysis stage (Ezzy 2002). The data analysis involved examining the transcripts of the fieldnotes and interviews and giving it codes (Gomm 2008)

Thematic analysis has been described using different terms by other authors but the process remains the same (Braun and Clark 2006, Ezzy 2002). Braun and Clark (2006) describe thematic analysis as having six phases, beginning with familiarisation of the data, generating codes and progressing to formally defining themes and then producing the report which allows final analysis (See Table 8).

Table 8: Phases of thematic analysis (Braun and Clark 2006 p97)

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Despite describing thematic analysis as a process with phases, Braun and Clark (2006) are in agreement with others (Creswell 2013), in that thematic analysis is not a linear process and that phases may need to be revisited, much like the spiral in Figure 8.

The thematic analysis process in this research followed these basic phases and provided guidance to the researcher while carrying out this form of qualitative analysis, to ensure the analysis stands up to questioning and is considered trustworthy and valid. These phases are now further described and illustrated with examples from the research analysis process,

The researcher was able to become very familiar with the data through the transcription process for both the interviews and all fieldnote data collected. Transcriptions occurred as close to the end of that episode of data collection as possible, with data transcribed from the researcher's notebook or from the audio recording of the interviews.

Following the transcription process of the observational fieldnote data or interview data, the researcher then started making initial codes, firstly as descriptive words or phrases. This involved the identification of topics from the data. A code is a word or a short phrase which assigns meaning to the data selected. Saldana describes a code as being 'summative, salient, essence-capturing' of a piece of data (Saldana 2009 p3). Codes were made by assigning a word or a short phrase to a portion of the textual data.

The researcher began with a lot of open or general codes, but these then became reduced down to groups of related codes as the analysis progressed and more data was collected (Brawn and Clark 2006, Ezzy 2002). The codes or themes at this point were very descriptive, focusing on elements which occurred regularly in the data, or the researcher thought to be interesting. There were many initial codes used at this point. Certain descriptive elements were used to start coding, for example clocks or time focused elements in the data, or certain words e.g. waiting. Consideration of both the interview data and the fieldnote data was considered simultaneously, however this developed as more data was collected and the time in the field progressed.

Further coding then took place and these initial codes began to be integrated across the data set into more central categories or more major themes (Ezzy 2002).

Initial codes focused on particular concepts or descriptive elements; for example, initial codes of clocks, times, machines, interactions. The analysis continued and the themes became more refined, with definitions becoming clear for each theme (Braun and Clark 2006). Some codes were more adequately explained or supported by the interview data, whereas some were more rooted in the observational data and fieldnotes.

Thematic analysis allows for a bottom up approach, where the data leads to generalisation or themes. This differs from content analysis, which is, in fact, the opposite with previously fixed categories to use for the analysis (Ezzy 2002).

Analysis continued as more data was collected and observations made in the field also then suggested new themes or codes. This included the researcher revisiting previously analysed data to review it with the new codes identified.

Analysis continued after data collection had finished, and the researcher had left the field as a researcher but remained as a member of staff.

Section 4.12.3 and Appendices 22 and 23 provide a detailed account of the data collection and analysis process, to show the overlap and order of the data collection and initial analysis elements.

4.12.2 Using Computer Software for Thematic Data Analysis

Computer assisted qualitative data analysis (CAQDAS) software removes the need for coding by hand, with multiple copies of the data on paper and using pens and post-it notes. It allows the researcher to identify a piece of text and assign it a code or label. The label can then be selected, and all pieces of text which have been given that label can be identified. This can be much quicker than filing and sorting by hand (Davies 2007). The software does not assign the identification of the codes or labels; this is still the job of the researcher. The researcher is still required to do rigorous analysis, as the software only facilitates the analysis process (Bazeley 2013, Bazeley and Jackson 2013).

The researcher used CAQDAS to assist in the coding or labelling of the written data collected as part of this research. The researcher had to look through the data as

closely as if coding by hand, and assign the labels to the data, both the written fieldnotes and the interview data. The use of software can help this process as when it is on paper, the data may be looked at more casually (Creswell 2009).

CAQDAS also can provide an easy way of searching the text, codes and nodes created (Bazeley 2007). The software can easily pull different things together, for example, one code or theme and all the data which has been coded thus, and puts it in one place. The researcher was able to use this function to check through all the transcribed and coded data at various points to look back at the large volume of data, to check for specific words across all the inputted data. It was particularly helpful near the end of the project and final stages of analysis to revisit the coded data, once the wider themes had emerged and developed from the initial codes.

The CAQDAS also helped to provide some distance between the researcher and the data. This may be viewed as helpful and also unhelpful. The use of a program can both be a barrier to being close to the data, which is important for data analysis but also can help in pulling back from the data to interpret what the data is saying. Allowing the researcher to distance themselves from the data helped the analysis process, particularly due to their insider position in the research field. Within this particular research, the initial data coding allowed some distance between the researcher and the data which supported the researcher's extrapolation from the setting and the data as they are an insider.

CAQDAS was also used to help begin the researcher in the thematic analysis of the data (Ezzy 2002). The CAQDAS software used for this research was NVIVO 10. This software was used to help code the data once transcribed. The data was input into the software and allowed the interview data and observational written data to be coded within the same programme as the data collection and analysis progressed through the research project.

4.12.3 Detailed Process of Data Analysis and Examples

The first data to be collected was from observation sessions. The first and second observations sessions were transcribed within 24 hours of their collection. Extensive notes were made on elements which had a particular focus on 'direct patient care' but

also included various aspects of the environment and the different events which occurred and who was present. Once the data was transcribed it was then input into NVIVO 10 and initial analysis commenced.

Two full observations were conducted before any interviews took place. The initial analysis started with this observation data, where the researcher read through and picked out interesting or contrasting events or interactions, things that were different and things that were the same. The observations also had a focus on using the original definition of direct patient care and elements which seemed relevant.

The individual interviews commenced, initially starting with a staff interview. It was important to ensure that any initial findings from the observation could be explored in the interviews. For the remainder of the data collection, observation and interview data were collected and initially analysed concurrently and this is detailed in Appendices 22 and 23. As ethnographic data analysis occurs throughout the data collection process and once the researcher has left the field.

The data was collected in line with opportunities which allowed data to be collected. When single rooms were available for patient interviews, these were prioritised and when opportunities with a room of consented patients presented themselves due to other external factors, not influencing this was also prioritised and utilised as much as possible. This is in line with the aim of ethnographic research not altering the research field, so as to collect the data naturalistically.

Annotated fieldnotes were collected during data collection and further annotations during data analysis. This supported the researcher looking at what had occurred in the session and allowing the researcher to move away from the data to aid analysis and the ethnographic approach.

The transcribed data was entered in to NVIVO 10 and was assigned basic descriptive codes. These codes then began to be grouped under larger categories and themes developed. Categories and themes were developed and realigned during the process of data analysis as new data indicated categories and themes for development.

All data was coded whether collected early in the process or later. All data and codes were then given equal weighting and influenced the data analysis and findings.

One of the first nodes was around care at a distance and the notion of ‘banter’.

Observation 1

‘You never asked me if I had any sores’ John says to the Nurse.’ ‘I can see the one on your hand yeh?’ the nurse replies. Archie, the patient next to John says loudly to the room ‘you better tell them about the one on my toe’ ‘aye the one on my toe John says laughing’ The patient is a bi-lateral above knee amputee and doesn't have any toes., The nurse and Archie laugh’

In the first observation session, the following was observed and labelled as banter.

Banter and humour became two separate themes within the final presentation of the analysis as part of verbal dialogue which occurs and is valued in the unit and is reported to be part of the wider concept of active care.

‘Care at a distance’ was a basic code which progressed to be part of the concept passive care. In the initial descriptive coding, care at a distance was used to describe various examples in the observations; the nurse checking blood results on the computer whilst looking at the patient over the top of the computer and also communication across the room between staff and patients during treatment time.

A response in an interview which also were coded initially into this category was that care was:

*‘Looking at their blood history, sorting out their folder, checking about what the dietician has been saying how they are getting on’
(Charlie, Registered Nurse)*

Another of the original descriptive codes used was for questions being asked in the unit, by staff or patients. Numerous questions were identified during observations, however these questions and way of communicating and contact then began to be

recoded, to align with other forms of communication or information provision, as part of larger themes.

Within NVIVO 10, the basic codes are identified as nodes. The node structure within NVIVO 10 was used to look at the data to assist in drawing out the wider concepts and themes which are presented within this research as results. A section of the final node structure from NVIVO is illustrated in Appendix 25. This node structure was then further adapted when dealing with the data as part of pulling the PhD together. There were several iterations of the node structure throughout the analysis process. Nodes or codes could be collapsed or combined, and then moved to be under bigger themes by using the programme. These themes were developed in discussions with supervisors when discussing and reviewing the initial codes and transcribed anonymised data.

Within the analysis, there were contrasting views around the same theme/node. They were treated under the same larger theme despite being contrasting perspectives/experiences. There were some contrasts between findings from observation and interview data in relation to relationships with staff. However, there was no attempt to observe and then interview the same staff or patients to look for congruence between the two methods of data collection. The one area that showed some interesting contrasts was relationships.

In interviews patients said they valued personal relationships with staff and spending time with them.

‘Sit down and somebody listens’ (Phil, Patient)

In contrast, some patients were observed to clearly send out signals that they did not want any interactions, as during observations, patients were observed to be sleeping or reading. Within interviews, patients identified ways of passing time on dialysis with something they wanted to do, rather than speaking to the staff

‘Listen to the telly, listen to music, so I use that time for me’ (Emma, Patient)

Within one interview, a patient commented that they did not want to disclose a lot about themselves to the staff in the unit during their treatment;

'I just don't believe in anyone knowing your business, I'm a private person that way (Judy, Patient)

The conflicting data from patients highlights their different expectations at the time of data collection and indicates that patients are not all the same, despite having the same condition.

4.13 Trustworthiness

Within qualitative research, trustworthiness is ensuring the research methods are dependable, credible, transferable and conformable (Holloway and Wheeler 2010). Trustworthiness is one way to describe the validation or verification of the research findings within qualitative research (Lincoln and Guba 1985). Doing this demonstrates the quality of the research presented.

Ethnography as a research design has been known to utilise various verification strategies as part of ensuring trustworthiness in the research (Rashid et al 2015). Within this piece of ethnographic research, four different strategies were used; triangulation, prolonged engagement, thick description and reflexivity.

The first three are now detailed, and member checking is also considered, however this verification strategy was not used in this research. Reflexivity is later considered in significant detail in Section 4.15 along with consideration of the researcher's position in the field in Section 4.14.

Also, considered as part of the trustworthiness process was the use of the researcher's PhD supervisors, for regular discussion and consideration of the elements of the research process, data collection and data analysis and is considered as part of outsider validation.

4.13.1 Triangulation

Triangulation is a method used to enhance the trustworthiness of qualitative research, which allows the checking of data sources by collecting data from others or by other means, allowing data collected at different points and from different participants to

be compared on the same phenomenon (Hammersley and Atkinson 2007, p183).

The strength of using multiple methods is that a total picture of the topic under study could be provided and the multiple ways in which the data was collected support and validate each other.

Considering this ethnographic research utilised data collected through observations, photographs and semi-structured interviews, the presented data draws on all these data sources to perform triangulation. Comparing data and concepts from observational data and interview data strengthens the research process, data collected and analysis.

Within the data collected, opposites were also highlighted when opposing views or different aspects were identified which opposed each other. Highlighted within the theme of verbal communication, there were significant views and occasions witnessed and experiences shared, ranging from lots of verbal communication and also very minimal or limited communication. One patient highlighted they did not want a lot of chat from staff, whereas others highlighted this an important aspect of their dialysis experiences. Mismatch across data and themes was considered important and remained highlighted, with its inclusion within the results reported.

4.13.2 Prolonged engagement

Trustworthiness is also demonstrated through the researcher's extensive and prolonged engagement in the research field demonstrated from the fieldwork conducted. By detailing the fieldnotes and raw data, readers can see the decision trail of a researcher within a research project (Koch 1994).

Within this research project, the researcher spent one month prior to data collection in the field, handing out information and providing staff and patient participants with the opportunity to ask questions, then gaining consent from willing participants. This time in the field as a researcher allowed for an establishment of the different role to be undertaken by the researcher, rather than the existing role of the registered nurse.

Following this extensive period of recruitment, 8 months were spent in the field. This was not only when data was being collected, but also on other days to plan

interviews and periods of observation. This prolonged engagement helped establish the researcher's position. The subsequent observational hours and interviews also allowed for a prolonged engagement with the field over this period. Conducting data collection over a period of 8 months highlights the researcher's engagement with the field and therefore suggests the volume of data collected and established trustworthiness through this process.

4.13.3 Thick Description

Thick description allows readers to make decisions regarding transferability due to the detailed accounts of participants and settings and allows the reader to have confidence in the findings and the researcher's interpretation of the findings (Geertz 1973).

Fieldnotes were transcribed as soon as possible to ensure that the data collected was as accurate and fair as account as possible. Within the fieldnotes, the researcher also kept notes as part of a research diary, to track the researcher's thoughts and feelings during the data collection, analysis, and this continued once the researcher completed the fieldwork and left the field.

4.13.4 Member Checking

Member checking or respondent/insider validation is another verification technique that can be used by the researcher to explore the trustworthiness of results in qualitative research (Birt et al 2016, Lincoln and Guba 1985).

Member checking usually refers to the giving back of either the transcribed interview or data following analysis to a participant, to confirm the credibility of the study data or account (Creswell and Miller 2000). Described by some in the literature as a 'crucial technique for establishing credibility' (Lincoln and Guba 1985 p314) particularly following a qualitative interview, member checking does also pose complications to the research process and therefore was disregarded for this ethnographic research due, to the complex nature of member checking in ethnographic research (Emerson and Pollner 1988).

The member checking process itself is a variable which may influence the research and findings (Sandelowski 1993). Members may not always be in the best position to check accuracy of accounts. Rashid et al (2015) have suggested that when they returned to participants for verification of the data, the participants had moved on with their lives and did not want to revisit the interview data.

The act of reading a transcript for accuracy may also because 'the member to revise his or her views and/or influence events still to be experiences in the course of the study' (Sandelowski 1993 p6). Particularly in this piece of research presented here, with the various data collection methods occurring during the 8 months in the field, involving the participants reviewing their data could have impacted on their behaviour or interview following the review of either raw data or interpreted results.

It has also been suggested that member checking should not be used as a form of verification when study results have been synthesised Morse et al (2002). Morse suggests member checks may invalidate the work of the researcher and force the analysis to remain inappropriately close to the data.

Willis (2010) argues that it is possible to present the perspectives of the participants, however they argue that this perspective is frozen in time, unaltered and this can be problematic when presented back to participants.

Member checking as a strategy for ensuring the trustworthiness of qualitative research is not recommended by Morse (2015). Within her paper, Morse suggests that the checking with participants post-analysis is not practical, and within the research presented here this was the case, due to the length of time following leaving the field and the full analysis being completed. This is particularly relevant within this paper, as unfortunately as some patients and staff who were involved in the study are no longer able to validate the results, due to leaving and passing away. Following the completion of the research and the completion of the analysis, discussion with the charge nurse who had supported the research occurred to share the results due to their planned departure from the unit.

Time in the field and working with people for long periods of time is what gives ethnography its validity and trustworthiness. Thick description of the environment and observations (Geertz 1973) helps to demonstrate this. The potential for issues to arise when considering maintaining positive relationships with participants following member checking has been highlighted (Carlson 2010).

One key individual who was thought to be in a position to do this was the Charge Nurse, who had a clear overview of care and practices in the unit. The Charge Nurse was approached following the completion of the study and subsequent analysis as one way of providing some validation from an insider. This particular participant was approached at this point so they were unable to change or affect their behaviour as part of the study depending on the results presented to them.

Considering offering the nursing staff or patients the opportunity to view the data would potentially compromise their position. There was also a concern by the researcher about participants being able to identify particular patients or staff from the data, which could compromise the professional position in the unit or the patients by revealing their thoughts to the staff or other patients, which would be unethical.

Staff participants have also read through some of the key findings and have been invited to presentations about the research and discussed the findings with the researcher. This has been used as an additional form of outsider validation following the completion of the research and analysis process.

Two key aspects of trustworthiness in ethnographic research are now explored. These are the position of the researcher and the use of reflexivity.

4.14 The Researcher's Position and Identity

The appearance of a researcher in a setting required consideration prior to conducting the research. Presentation of self (Agar 1996) or impression management (Hammersley and Atkinson 2007) is an important aspect of ethnographic research.

The researcher was considered an insider within the particular setting and group under study. The researcher had dual practitioner-researcher identity. The position of the researcher was highlighted within the research process from both participants

and the researcher herself and this is illustrated within the reflexivity section, considering the dual role and position and the impact it had on the research process and data collected.

Role confusion in insider research can occur due to the familiar setting, where the researcher has an existing role and is known to the setting or organisation. This was particularly a concern in this research project, due to the researcher's position in the area as a nurse and colleague, and the participants knowing the researcher in this capacity. Various different strategies were employed to prevent role confusion and its influence on the research.

The researcher identified themselves by wearing a different clinical uniform on observation sessions. This was to visually identify to all in the unit that the researcher was different and not wearing the regulation nursing uniform. Scrubs were chosen to be worn, as these complied with infection control guidelines, and should the researcher be required to participate in any emergency situation, their clothing would not compromise this position.

The researcher was required to constantly tell potential participants, patients and colleagues, the position they held when they were in the unit. The researcher would explain either that today was a working day, or a research day. On working days if potential participants wanted to discuss the research and their potential involvement, then the researcher would come back to them on another occasion when they were in the unit as a researcher. This ensured that the research was conducted in line with ethical guidelines and their clinical position did not become blurred into the research position.

This also happened in reverse, when patients would ask about treatment or other aspects like changing times of treatment or vascular access concerns, and the researcher would give short answers, so as not to be uncaring or unhelpful, but then direct one of the members of staff toward that patient to follow up their particular questions. This is similar to other researcher reports presented in work by Hay-Smith et al's (2016) systematic review on dual-role clinician-researchers, where clinical queries were posed by participants to the researcher and also in Hiller and

Vears' (2016) work reflecting on patient misconceptions and confusion on the clinician researcher role.

Within the semi-structured interviews, the researcher always gave the participants the opportunity to mention anything at the end of the interview. For some patient participants, this appeared to be an opportunity to talk about real problems they had experienced, such as transport or waiting times, and potentially this was viewed a way for the patients to voice concerns to a member of unit staff.

The consideration of the researcher position prior to entering the field was imperative to the success and trustworthiness of the research, data and results. Had this not been extensively considered, the researcher may have inadvertently affected the research.

4.15 Reflexivity

Reflexivity is the process of reflection throughout the whole research process by the researcher through self-critique and self-appraisal (Koch and Harrington 1998). This section discusses reflexivity and its use within this research. It will be written in first person, due to the nature of the topic and the use of the researcher in relation to the research.

4.15.1 What is Reflexivity?

Reflexivity is an integral part of all qualitative research methodologies, referring to the position and the influence the researcher has on the research process and its findings and having the awareness of this influence (Jootun et al 2009, Finlay 2002a).

Reflexivity is an aspect of qualitative research practice which requires significant time and attention by the researcher before, during and after the research has been conducted. This is a part of research practice that is important and relates to the researcher and their conscious reflection. It concerns how they shape and are shaped by the research process, analysis and the research findings. By ignoring reflexivity, the research could potentially be regarded as not trustworthy and the results not dependable or credible.

Dowling (2006) describes reflexivity as a ‘curious term with various meanings’ (Dowling 2006 p7), illustrating the potential uncertainty of the definition of reflexivity for researchers, although some have defined the concept. Finlay (2002b) simply defines reflexivity as ‘thoughtful, conscious self-awareness’ (Finlay 2002b p532).

Reflexivity encourages self-awareness and the evaluation of responses or data collected. It allows for the researcher to see the data collected subjectively, rather than regarding it as objective which has not been influenced or shaped by the researcher conducting the research. These influences could be the researcher’s values, behaviour, actions or just their presence in the research setting, affecting data collection and also analysis.

The choice of methodology, setting or participants studied also impact on the researcher and their interactions, which therefore impacts on the research project and the data generated. This must be acknowledged as part of the reflexive process (Cruz and Higginbottom 2013). All qualitative researchers have an influence on the research and are involved in the co-construction of the research data with the participants and their relationship with the researcher (Finlay 2002a).

The researcher should be able to step back and examine the effect of their existing ideas and beliefs, although this is not an easy task to achieve. The researcher must also be aware and reflect on how the data that has been collected is influenced by the respondents’ perception of the researcher.

Reflexivity is more than reflection

Reflexivity is much more than a process of reflection by the researcher throughout the entirety of the research (Finlay 2002b). Reflexivity is not just looking at how the researcher has conducted themselves; it requires a deeper review and is a more active process (Dowling 2006). Reflexivity is difficult and challenging for the researcher to engage with. The researcher requires identification and questioning of their own personal and professional practices and this requires time and effort (Finlay and Gough 2003).

Finlay (2002a) suggests five variations within the idea of reflexivity; the exploration of the researchers own experiences to further insights into research (introspection), looking at the relationship between the researcher and participant (intersubjective reflection), the participants being a part of the research and their own reflection having an influence on the data collected (mutual collaboration), the power relationship in the research and the social position of the researcher (social critique) and the language, their different meanings and the potential for this to occur within the data collected (discursive deconstruction).

These five ways to engage in reflexivity illustrate its complex nature and the different ways in which a researcher can engage in reflexivity. These different ways, however, all allow for the researcher to take account for the decisions made and the impact the researcher and methodology has on the data and research process (Finlay and Gough 2003). Some of these ways to construct reflexive analysis are more appropriate depending on methodology choice and theoretical ideas.

Reflexivity is a way to add trustworthiness to the qualitative research and the data collected by acknowledging the potential actions from the researcher which can affect the data (Dowling 2006). Reflexivity does not remove bias, but acknowledges that bias exists and with conscious awareness of a researcher's impact, can allow the study to be seen as transparent, with no information hidden to cause concern over the reliability of methods or results (Freshwater 2005).

4.15.2 Reflexivity within Ethnography and Fieldwork

Reflexivity has been seen as an important aspect of ethnography since the 1970's, where prior to this, a researcher's presence and influence on the research and their position was to be almost eliminated from the final findings (Davies 2008). Personal references were carefully avoided to maintain the positivist orientation of ethnographic work and for the research to be seen as purely objective. This position did not allow the researcher to acknowledge the impact and potential distorted view which could be presented.

Reflexivity has been a focus and is now considered part of good ethnographic practice in establishing the researcher's integrity within the setting under

investigation (Arber 2006). Ethnography allows research data to be collected from the researcher participating within the setting and still be seen as trustworthy. One advantage of ethnography is the researcher's involvement in the setting under study (Coffey 1999), as long as the involvement is acknowledged through reflexive practice. The researcher's position, place and identity require to be understood and the judgements which have been made are reflected through the immersion within the setting which therefore can allow for trustworthy results.

Pellatt (2003 p29) quotes reflexivity as a way of adding 'plausibility or rigour to the ethnographic research'. O'Reilly (2012) suggests that ethnography cannot be undertaken without the acknowledgement of the individual's role of their 'own embodied, sensual, thinking, critical and positioned self' (O' Reilly 2012 p100) which suggests the requirement for reflexivity in the research process.

From the involvement in a group or culture conducting observations and participating within the setting and developing relationships with the participants, the researcher has an impact on the research just by doing the project. The researcher's presence will impact on the results and this requires to be understood through reflexivity. Pellatt (2003) suggests that as a nurse conducting an ethnography within an area in which they had considerable knowledge and expertise was a benefit, to allow insight into the area. However, this knowledge and expertise must be acknowledged and understood to ensure the effect of it on the research and the data is fully recognised.

Reflexive analysis is a problematic process and can be complicated. It requires commitment, time and skill from the researcher to ensure it is done well (Finlay 2002b). The researcher is the research instrument when conducting an ethnographic project so reflexive analysis must be engaged with.

To demonstrate the researcher's reflexivity, the three stages used by Finlay (2002b) within a paper will be used: the pre-research stage, the data collection stage and the data analysis stage. Whilst the data collection stage and analysis did occur simultaneously and was not quite as linear a process (see section 4.12), it is useful to separate them out to understand the different elements of the reflexive process which has occurred as part of the research.

This section will be written in the first-person narrative, to illustrate the researcher's position and feelings on the research process and their influence on the setting and data.

Pre-research Reflexivity

Reflexivity or reflexive analysis begins from the moment a research idea is conceived. The researcher should identify their own existing relationship with the topic, identifying forces that might skew the research in particular directions (Finlay 2002b).

I needed to clarify my own position within the research before I even started, and examine my motivations, assumptions and interest in the research topic. For me, this was quite a difficult thing to do, but extremely worthwhile. I had already considered some of my preconceived ideas and motivations within PhD supervision sessions. I have been aware for some time that I had ideas about the care that patients were receiving within the setting, due to my clinical experience and from informal chats and discussions with patients in the way in which I provide care. It is because of this that I chose to explore the patient and staff views on direct patient care and what these groups view as important. I knew if I did not acknowledge these thoughts in the initial stages of planning the research and continued it through the research process that it could skew the results and make the data untrustworthy (Finlay 2002b).

I needed to ensure that I identified factors which could impact on my ideas about the research project. One issue that I have had to contend with is the views of a key staff member that has had a negative impact on me and I have been very aware of not allowing this to impact on my feelings prior to any data collection.

By examining my assumptions about the direct care which I believe occurs in the unit, I have begun to distance myself from the staff group slightly; to maintain my research role and not just fulfil my clinical role whilst in the unit, to conduct research activities either consenting or providing information, as well as the formal data collection sessions.

I was always aware of the necessity to identify my different roles when in the setting and having to fulfil a variety of different roles. Pellatt (2003) describes the acceptance as a researcher into an area they already had an existing role within the field and acknowledges the difficulty in separating the role of the nurse and the researcher. From my own experiences, I echo this difficulty, as being a nurse in the area in which I carried out the study has affected the research and affected the role I took when carrying out the data collection. However, from using reflexive practice, I believe that this affect is minimal and can still allow the findings from this research to be trustworthy.

I am a nurse, and I cannot change that. I am a caring person, and cannot stand to the side and not acknowledge my patients and staff. I also have a duty of care to my patients which would be acted upon should it be required during data collection. Due to my awareness of this, I would write and reflect upon a situation that arose, to ensure I understood the situation and my impact has had on the research.

Another way in which I reflected upon my potential engagement in the field before I had started data collection was my choice of attire. I decided on wearing scrubs for my data collection sessions, so I remained in a clinical uniform, but not my staff nurse uniform. It was hoped that this physical difference would acknowledge to my colleagues and the patients that I was doing a different job, but would still remain in a clinically acceptable outfit, in case I was needed to be involved in patient care unexpectedly e.g. a cardiac arrest situation.

I also considered how I would write down my data and fieldnotes prior to data collection and now that I am considering reflexivity, my use of a pink notebook to collect my data and write my fieldnotes is something which requires some reflexive analysis. The pink notebook is A4 and I write in it during my observation sessions rather than after the sessions. I chose the notebook as it was big and pink is my favourite colour, but I did not consider the colour would have an effect on the participants. The notebook I had thought would stand out and is almost used as a prop to identify my presence as a researcher and symbolise that I am doing something different to my clinical work.

Reflexive Analysis on Data Collection

Reflexivity in the data collection aspect of the research process involved looking at the way the data was generated, looking at what was seen and said from the fieldnotes and interview transcripts but also what was missed or not written and the impact of the researcher's presence and actions. This allows for the exploration of the process and the outcomes of the data collection process and the relationships which have developed as part of the research process.

My own awareness of my position within the research process is similar to one Finlay (2002b) describes when she was conducting research with a group of professionals in which she was one such professional. From incidents with participants, Finlay suggests that she needed to work out in when she had shared understandings from her own professional beliefs and also when her beliefs or understandings differed from those of the participants.

One question which should be asked when being reflexive of the data collection process is how has the researcher influenced the informant when collecting data? It is hoped that from the data shared in this section, there was an indication that I was aware of my position and how I may have affected the participants, the data collected and the analysis. Different examples are used from both interviews and fieldnote entries to illustrate different situations and the researcher's reflexivity.

12.15

Marie-Anne (Staff nurse) is taking Ross off the dialysis machine. He asks 'can someone hold my top one'.

***This means the top site where the needle has been removed from the fistula. Not all patients can hold their own sites once the needles have been removed, especially those who are more elderly and frail or have issues with their hands and grip. Marie-Anne was washing the machine to the patients left, and not looking or talking to the patient, so she washes her hands and then starts to hold the patient's arm. She does this without verbally responding to the patient but her actions appear to indicate enough to the patient that she is going to do as he has asked.*

The needles had been out for 10 minutes approx and the bottom site had already stopped bleeding, but the top site was still bleeding and needed more pressure applied for longer. The site appears to be bleeding more than expected, and there is blood all over the patients arm and on the pad which the arm is resting on. The normal practice is to apply more swabs to the site and hold it for longer but the swabs are saturated with blood. I can see that Marie-Anne needs some assistance but she cannot go anywhere as she is holding the bleeding fistula site. There is no one else available in the room to get equipment from the trolley which is about 10 feet away so I get up to get the equipment for Marie-Anne. I open the packs up and put them out and also offer a suggestion of advice to use another type of dressing which I have also laid out which will help stop the bleeding 'take that off, use this and start again' I say. Marie-Anne is an experienced nurse but I want to make sure she is ok with the current situation and offer advice. I then wash my hands beside the patient and then sit back down with my notebook and continue the observation

Ross: you're meant to be watching (to me)

Marie-Anne: 'bet that's given you something to write about (making a joke)

Ross: 'I had to oblige'.

This section of transcribed fieldnotes was taken during the first observation session in this research. This section from an observation session shows a situation between

a patient and staff nurse where the presence and participation of the researcher had an impact on the participants.

I can see from my response to Marie-Anne that, although I did not notice at the time until I wrote it down, I had used my position and experience as the more senior nurse in this situation by getting the equipment but by also telling her what to do. This was at the end of the observation session and I have not observed her since or seen her at work, so I am unsure the effect this will have on the research going forward but has illustrated to me the difficulty in remaining in the research role and not being involved and how my presence can affect the research.

The comment from the patient saying albeit jokingly ‘I had to oblige’ shows the participant’s feelings to perform for me as the observer, although strangely when I examine the data collected from the patient during that session, I do not believe he was trying to perform during the observation. This statement was used to acknowledge that the researcher was there in a different capacity and that the patient felt that that there had not been much happening to observe this session, which was certainly not the case.

During some of the interviews, the participants used different ways to highlight my dual identity and previous and existing clinical role. Some participants viewed the researcher’s presence positively and some negatively, despite them providing written informed consent to participate in the research project.

There was also a concern that responses may be provided by participants, answering in the way they think they should respond, rather than with their true beliefs. The researcher was not in a senior or promoted post within the setting. This junior position allowed for patients and staff to respond to the questions about care in a way they are happy with, without any pressure to say what they think they should say if a manager was interviewing them.

From considering the research and the way the research was conducted, maintaining reflexive practices throughout the study, taking notes and detailing the thoughts from the researcher helped to ensure a more research-focused relationship, rather than the

existing clinical relationship with participants. This has added to the trustworthiness of the findings.

One patient used his experience of seeing me in a clinical setting from when he first began dialysis treatment to highlight my knowledge and experience and that I have looked after him previously.

'You yourself were up there once, telling me I should be on a bigger dialyser' (Jerry, Patient)

This quote from Jerry highlighted that despite me not being there in a clinical capacity, the patient still associated me with his dialysis experience and that I had knowledge in this area.

Edward used an example of knowing about something I do in my spare time to highlight how he has got to know the staff in the area and that this is important to him.

'A nurse shows an interest in your private life, without intrusion, you feel interested, and it works both ways, like you and your dancing, and Janice (nurse) and her country dancing' (Edward, Patient)

I had not considered that patients knowing small bits of information about me as a person was so important to patients.

Phil commented on my nature as a nurse, and that the time I spent with him by sitting down and listening was hugely valuable to him.

'I mean you come in here and have a chat with me' (Phil, Patient)

Sandra commented on my personality and how this is an important aspect for her and her treatment experience.

'They keep the place going, like yourself, a bubbly wee lassie, well I say wee lassie! Keep the place going, keep you going' (Sandra, Patient)

Emma highlighted my change in experience, and that all staff start off in the area as new and inexperienced but that the patients grow to trust us

'we do gain confidence in the new ones as time goes on, like with yourself, you were new to us, but you are part of the furniture now'
(Emma, Patient)

One aspect I had not considered was that both the patient participants and the non-participants would be concerned and interested in how the research was going.

Fieldnotes- Observation 2

'things going well then?' Al (patient) shouts across the room at me, I stick my thumbs up towards him, 'that's great' he responds

During both the fieldwork days and my clinical days, patients who had consented and also not consented would ask how things were going or how I was getting on. Whilst I had thought that staff might take an interest in how things were progressing, I had not considered that patients, despite their differing involvement in the process, would still be interested in what was happening or show an interest in my work or progress. This highlighted the patients in the area do have an interest in the staff who work there.

During an observation session, one of the healthcare support workers identified during an observation what he was going to be doing.

Jon, the support worker in this room, is off to the machine room – he tells me where he is going. 'I'm need to do the machine room' he tells me and smiles, and then walks and leaves the room. He doesn't tell the registered nurse working in the room who is sitting at the desk, he just tells me.

This situation made me aware that staff wanted to include me in what was happening, and also potentially make sure that I knew what staff were doing. Staff do go between the rooms to do different jobs, but this particular situation identified to me that staff did not want me to either guess or misinterpret what their actions were at times.

During informal chat with Deputy Charge Nurse Karen:

I think, do you think? Do we have to look at the down time? I noticed it really bad, they are sitting at the desk doing nothing, having a chat, and it was really noticeable, go and chat to the patients, include them in the conversation, you are sitting with your backs to them

***She asked my opinion and views on the down time and staff behaviours during this time.*

During an interview with one of the registered nurses, acknowledged the researcher's experience and position within the unit and asked her position on the staff behaviours and what should be done. The aspect of the fieldnote which is highlighted by a * is my own thoughts during the fieldnotes from this particular conversation. I was aware at the time that this member of staff had included me and was looking for my opinion on the situation and current practices.

I was unable to change my position or standing within the area due to my experience, but highlighting some examples of the understanding and acknowledgement of my position will allow my results to be trustworthy.

Reflexivity on Data Analysis

Data analysis occurred during the data collection and fieldwork period, and continued after the researcher left the field (See Section 4.12). As previously explained, whilst the data collection and analysis did not happen in such a distinct and linear process, they are separated here to demonstrate the researcher's reflexivity specific to this particular aspect of the research process.

Reflexivity at this point is examining the researcher's responses to the data and the ideas or contradictory ideas about the data or participants.

I will now show some comments and fieldnote entries from when I was carrying out the second observation session, which illustrates my position as the researcher and observer, and the staff's perspectives of my presence, showing the need to be reflexive to examine their and my responses in full.

The first statement within this section of fieldnotes was made by a senior nurse who was having her last shift before retirement.

09.50 I'm sitting in between space 3 and 4, beside the entrance into the room from the main unit.

Helen (senior female staff nurse) comes through into the room from room 3 into room 4, and approaches the nurses' desk. She looks at the desk and the notebook, looking at the list and the times of the patients finishing treatment. Noreen does not ask or say anything to the staff sitting at the desk, there is no verbal communication between them here. She turns round and walks back towards the exit where she came in, which is past me. Whilst she passes me 'You look comfortable in that chair, you could sit there for the next 40 years until you retire!'

This comment from the nurse is her way of highlighting my difference in role and that I am sitting and she is not. It also goes against the views that nurses are always on their feet and busy, as I am looking so 'comfortable'. I did not respond to the comments either, so this will have had an impact on the staff member, although as she is no longer working within the area, she is was not part of the study for more than this one observation session.

(sitting with my notebook, on a plastic chair between two patient stations)

Sylvia turns to me, 'Are you hiding?' I smiled back, 'you have found your rightful place' she says.

A comment made by Sylvia, a female staff nurse when I was conducting my second observation session. This session I had changed my position to be at the outside of the room in the patient area, rather than at the desk where the nurses are mostly situated.

One reason I had moved was because when sitting at the desk I became involved in the nurse's daily activities and staff were trying to include me in their conversations, which was not allowing me to distance myself and observe the room and what was

going on. I believe this staff member was establishing their role and mine within the room for the session, as they may have felt as I was an intruder watching them and that I was less than her due to my sitting on a chair not at the desk to observe. I responded to the nurse with a smile, as I did not know what to reply and was aware that I did not want to get into a situation where I was defending my position as researcher in the middle of the data collection session. I had not considered this lack of response as something which would affect her views on me for the rest of the project and beyond. As I have not questioned or defended the comment, it compounds the idea that I am in a less powerful position to the staff nurse during the research project.

08.45

Frank (Staff nurse-male) walks past me from Kieran to Craig (Patients), and as he passes he says 'so you being lazy today or just working' and then starts to chuckle. He walks to Craig and has a quick look at his folder then discards it back on to the top of the machine and then sits back down at the desk.

This small encounter illustrates that although this staff member has provided written informed consent and has taken part in an observation session; he has highlighted my presence and difference as laziness rather than a valid role and has wanted to say something to belittle my position as the researcher. This action from the staff member moving between the two patients appears to be purely to make a comment to me and does not serve any other purpose.

Another situation where staff have used comments and behaviour to highlight my difference in role

'Ah just sh*t myself- I didn't see you!'

***** Jim shouted this loudly to all the staff and patients who were in the room, one patient looked up startled.***

This comment was surprising at the time, as this member of staff knew the researcher was in the room doing data collection, as he had already spoken with me only 30 minutes prior to starting this particular observation session. From reviewing the fieldnotes on this particular incident, it is clear that the charge nurse is trying to draw attention to the researcher and show his superior position to myself. He also did it in such a way to try and get the attention of the staff and patients in the room, although all the patients were asleep or listening to iPads, iPods or music and using headphones, so they did not hear. I believe the charge nurse here wanted to make his position in the room more senior to mine and also highlight my presence to everyone in the room. I believe he may have been threatened by my presence as a researcher, and potentially as a female. For the remainder of the study, the Charge Nurse was not met again.

4.15.3 Summary of Reflexivity

Reflexivity is a part of all qualitative research, referring to the position and the influence the researcher may have on the findings (Jootun et al 2009). Reflexivity is the process of reflection by the researcher, considering the thoughts and actions of the researcher and their impact on the research throughout the whole research process. It is a way to add trustworthiness to the data collected and the research by acknowledging the potential actions from the researcher which can affect the data (Dowling 2006). This could be their values, behaviour, actions or just their presence in the research setting, affecting data collection and also analysis.

The researcher should be able to step back and examine the effect of their existing ideas and beliefs, although this is not an easy thing to do. The researcher must also be aware and reflect on how the way in which the data which has been collected is influenced by the respondents' perception of the researcher.

4.16 Leaving the field

Once the research has finished, the researcher requires to leave the field and terminate the fieldwork. This is the end of the period of data collection and, within this specific research project, was dictated by the end of the project IRAS ethical permission.

The researcher was required to explain to the staff and patients that the research had concluded and that no more data collection would be taking place.

Three patients had expressed interest in participating in a semi-structured interview when they were receiving haemodialysis treatment, but due to requiring to use the cubicle within the area and other patients requiring this particular space, the interviews were not able to be conducted.

Ethnographers rarely leave the field unaffected by the experience of conducting research and being in the field. Following the completion of the fieldwork, some annual leave was taken so as there was some distance between the end of the fieldwork and the researcher returning to the field as a staff member.

Difficulties were experienced by the researcher once the field was left. This was due to their continuing as a member of staff in the area. All participant groups continued to ask what the results were and if the PhD was finished. This continued for two years, following the end of data collection whilst analysis and writing up was occurring.

4.17 Chapter Summary

This chapter has detailed the choice of research design, methods and theoretical perspective employed to answer the specific research aim and questions.

An ethnographic approach was used from an insider research position, to obtain the perspectives of all groups within the haemodialysis unit in relation to direct patient care. Participant observations including photographs, informal questioning and fieldnotes, along with semi-structured interviews, allowed for data to be gathered and analysed to answer the research questions. The research was carried out in line with the ethical permissions granted.

The way in which this research was carried out, data collected, analysis undertaken and the researcher's reflexive approach can suggest the trustworthiness of the process, and therefore, the findings which answer the research question. The next two chapters detail the findings of this study.

Chapter 5 Findings: Context of Haemodialysis

5.1 Introduction

The findings from this ethnographic work are presented over two chapters. This first chapter helps set the scene and illustrate the context of the haemodialysis out-patient area. Following this, Chapter 6 is a second findings chapter, which presents the findings that are specifically related to the original research question.

It is considered an important aspect of ethnographic work to provide a basis for understanding the research conducted, and the setting in which the ethnographic fieldwork was conducted. In this chapter, the haemodialysis unit context is described to provide an understanding to the overall context.

Data is presented using interviews, photographs, informal questioning along with thick description fieldnotes made during the fieldwork to illustrate that the researcher has ‘been there’ (Geertz 1973). By including this raw data, it can allow others to make judgements about the authenticity, transferability and trustworthiness of the findings. This research data was collected by the researcher being ‘in the field’ from December 2013 until August 2014.

All the written data presented here is anonymised, with pseudonyms used for all the participants, so that no participant can be identified. The data is presented dependent on the participant and the method of data collection, to clearly show who gave the response and how it was gained from the participants (see Figure 3 and Figure 4 in Chapter 1.5 ‘structure of thesis’).

5.1.1 Structure of this Chapter

This chapter will begin by describing the haemodialysis environment, including the rooms and the important objects found within this area. The staff within the unit are then described, followed by the findings which identify the patients providing in-depth understanding of these groups.

An important finding presented in this chapter is described as the rhythm of care, with the routine of usual events being highlighted. The rhythm of haemodialysis

describes the pattern and predictability to the way in which haemodialysis care is carried out in the unit.

5.2 The Haemodialysis Environment

5.2.1 The Main Renal Unit

The haemodialysis unit in which the researcher undertook ethnographic fieldwork is considered or described as a main renal unit, rather than a satellite renal unit.

The unit is a large main unit and has 46 haemodialysis stations, which can be used three times a day. Most patients require to attend three times a week- usually every second day. Patient arrival appointment times are 0800-0900, 1330-1430 and 1830-1930. Prescribed haemodialysis treatment in this unit varied from three hours to five hours and was dependant on medical assessment and patient needs.

The nursing staff usually work shifts at 12 ½ hours, with a start time of 7.30am or 12.30pm. There is a mix of full time and part time staff, with two support workers who do a combination of long and slightly shorter shifts.

A diagram which shows the entire unit and how the rooms are located can be found in Appendix 9. There are some communal areas which all patients will usually use before and after their haemodialysis treatment.



Figure 9: The waiting area

Patients arrive at the unit through the main entrance door from outside, which leads to a waiting room/reception area. There is also an alternative route to the reception area from the main hospital through an out-patient department corridor. This reception or waiting area (see Figure 9) is where patients will arrive and wait before and after their treatment. Within this area, the ward clerk and the holiday coordinator are situated behind the main desk.

‘Reception, is different, it’s like a different rule when you come through the door’ (Jerry, Patient)

‘The woman we have a wee blether when we are waiting (in the waiting room), you can’t really have a blether ⁴in there (dialysis area), can’t shout across, you know what I mean, it’s a bit hard’ (Judy, Patient)

Patients identified that things were different in this area, and that patients would talk to each other here, but not necessarily as much when they are in the clinical space.

From this reception and waiting area, there is a set of double doors, which provides the main entrance into the clinical haemodialysis area. Through these doors is a main corridor, which leads from the reception area for the different haemodialysis rooms.

From this reception and waiting area, there is a set of double doors which provides the main entrance into the clinical haemodialysis area (Figure 10). Through these doors is a main corridor, which leads from the reception area for the different haemodialysis rooms.

Above this set of main doors is a red sign which states ‘no unauthorised access’, with three notices which display information about appointment times, a request to stay in the waiting area until staff have called patients into the clinical area and how to contact the charge nurses.

⁴ Blether is a Scottish term for chat or conversation to talk long-windedly without making much sense



Figure 10: Main doors to the clinical haemodialysis area from reception

At the end of this corridor are the scales, where the patients weigh themselves before and after their treatment and a water cooler for patient use (see Figure 11). The linen container is also located in this area. It contains all the clean linen for the unit and is replaced twice a day by the hospital staff porters.

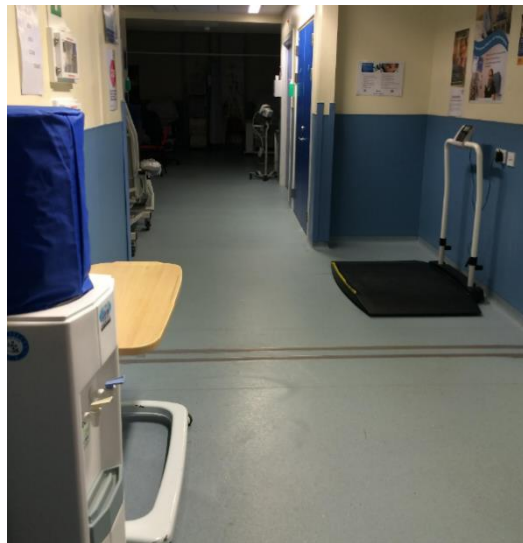


Figure 11: Area with scales and watercooler

5.2.2 The Haemodialysis Area

The haemodialysis area is the clinical area where the haemodialysis takes place. This is the area where the observations took place, and is the main site of the direct

patient care, where patients and staff spend their time together while treatment is being carried out.

During the research the different elements of the haemodialysis unit environment were an important part of the data collected. The environment is where the care takes place and had an impact on the care delivered in the area. The diagram of the entire unit shows the main patient areas in relation to each other (Appendix 9).

Haemodialysis Rooms

There are five rooms in this particular main haemodialysis unit, each room having between seven and eight haemodialysis stations.

Some rooms have specific identities, as one is the room used for patients with infections as a cohort room, and one room has a particular focus on self-caring practices, less nursing input and support for potential home haemodialysis patients.

Each haemodialysis room has similarities with the haemodialysis stations, referred to in this unit as spaces, being around the edge on the walls of the room.

The nurses' station, or main desk, is also in a prominent location, in a location where if at the desk, most patient stations can be seen. In two of the haemodialysis rooms, the desk is in the middle of the room and in the other rooms the desk is at one end of the room.

The rooms are referred in the unit by staff and patients as room 1, room 2, room 3, room 4 and self-care. The 'self-care' room is where patients predominantly do their own dialysis care with minimal assistance from nursing staff. Usually there is one registered nurse and one healthcare support worker allocated to this room on a daily basis.

Room 1 is also sometimes referred to as the infection room. This room has four main haemodialysis stations, and then a further four spaces split between two smaller rooms or cubicles. Room 1 cares for the haemodialysis patients who have infections and require isolation. This room is used as a cohort room for patients who require to be isolated from the rest of the unit and other patients. This room is slightly different

to the others, as this room was a recent addition to the renal unit due to increasing numbers of patients and the requirement for more isolation stations. The desk in room 1 is smaller and faces the wall, which has a window in it looking into one of the two smaller rooms.

Room 2 is regarded as the main room, where the co-ordinating nurse is usually based and the main unit phone number used is the phone number for room 2. It also has the medication fridge for the unit located behind the desk, so staff from all rooms use this fridge. Within this room there are eight dialysis stations and two of these spaces are single cubicles for individual patient isolation (e.g. post-holiday isolation). These are also the cubicles which were utilised to conduct the patient participants' interviews.

Room 3 has eight haemodialysis stations and links between room 2 and 4 (Figure 12). Room 4 has seven stations. Room 4 has an emergency exit into the main hospital, which is used by staff to enter the unit with their pass cards (Figure 13). Some patients also use this as an exit route to leave the unit following their treatment.



Figure 12: Room 3



Figure 13: Room 4

The layout of the room was something which had an impact on the patients, one patient felt the room and the staff doing things nearby positively impacted on her.

'The closeness of the room and the desk in the middle, and always somebody there and they are beavering about' (Betty, Patient)

Whispered Conversations

The layout of the haemodialysis room and the close proximity between patients when attached to the machines had an impact on the care provided within the dialysis unit area. It is known that the rooms and machine positions do not allow for private conversations for patients when they are attached to the machine.

The dialysis spaces in the main rooms are quite exposed and patients know that others can hear what they say so are careful about what they say at times.

'You know whatever you are going to say, is going to be heard by every single person in the room, so I would be a bit hesitant to talk about anything, very personal, depends how embarrassing or confidential it is, wouldn't want to say, even behind the curtains' (Donald, Patient)

The staff know this is an issue, but due to clinical needs of patients requiring isolation and due to not knowing if patients are going want or require a private chat, once a patient is on a machine, they cannot be relocated or moved into this private space.

'You couldn't just suddenly just change someone's dialysis and say oh I want to have a conversation I'll just whip the whole thing in there'
(Darcy, Registered Nurse)

Patients also suggested that despite others being able to hear their conversations, the layout of the rooms also did not always facilitate having conversations with other patients.

Patients accepted that this is just a limitation which they have to work with and accommodate.

'It's the way dialysis works, you can't always sit in a huddle and have a chin wag' (Martha, Patient)

The layout does not allow for conversations with other patients and had an impact on their interactions with each other when they were receiving haemodialysis treatment. Figure 14 shows from one dialysis space to another, indicating the distance between patients.

'You are quite far away from the person next to you, sometimes they are hidden by the machine, so you can't really sit and chat, sometimes you can shout to the person who is opposite you' (Donald, Patient)



Figure 14: Distance between the patients when on haemodialysis

Patient Areas and Staff Areas

Within the haemodialysis rooms, the patients would usually remain in this space or the surrounding area, due to the nature of the treatment and being attached to a non-movable machine. Staff tend to sit beside or behind the desk, sitting on the chairs at the computer.

Patients are usually attached to their machine, or in the pre or post dialysis phase, waiting for things to be ready, getting organised and comfortable or to stop bleeding and blood pressure checking.

During treatment, the patients have a variety of different ways to pass the time during their treatment; some sleep, some watch TV or listen to music. Others bring in magazines, puzzle books or other reading materials. Portable computers, laptops and tablet computers also provide patients with activities to keep them busy during treatment. A few patients bring in work to do and make phone calls for business.

Different areas have different rules or expectations, the waiting area/reception is for more chat whereas the dialysis areas are quieter and people respect the time when they are on dialysis.

5.2.3 Regular Dialysis Spaces

The regular dialysis spaces are allocated on a weekly basis. A meeting is held on a Wednesday to allocate new patients to any empty spaces. This meeting considers all the patients at the satellite units as well as the main haemodialysis unit, and regularly monitors the waiting list of patients who are nearing the point of requiring dialysis treatment.

Morning, Afternoon or Twilight Slots

Patients normally attend the same shift each session, alongside the same patients.

Patients who are prone to being unwell or have had complications with treatment are usual attenders for the two shifts during the day, either morning or afternoon, with more stable patients attending on a twilight shift. This is considered due to the lack of renal medical staff in the hospital after 9pm and chances of medical or dialysis complications and therefore requiring support.

The shifts which patients attend for treatment can have an impact on the care delivered in the unit. One registered nurse felt that the shifts in the evenings, which had fewer patients, allowed for more active care to occur, as there are usually fewer patients and fewer things to do. There was also more space between the patients as not every dialysis space was used. This could allow more chats between the staff and the patient.

'It's easier on a twilight, cause you don't have a full room, or not very often' (Angie, Registered Nurse)

'You tend to respect people's space when you are in the room erm, obviously there are people you can have a natter with, they tend to like to get on and be quiet' (Jerry, Patient)

Donald started on an afternoon shift, and then moved to an evening/twilight shift. He felt that the evening shifts had a different atmosphere to the afternoon.

'It was better on the afternoon shift' (Donald, Patient)

Donald acknowledged here, that being used to the groups that you dialysed with regularly was important and impacted his time when in the unit on haemodialysis.

'The people that I was used to on the afternoon- they are chattier' (Donald, Patient)

The different atmosphere from the evening twilight shift to the day shifts could be due to the differences in staff numbers, the non-presence of regular medical staff past 5pm, and the patients who were required to be more medically fit than the patients who attended during the day shifts.

'It's definitely much quieter, on the twilight, if you want to relax, I would say the twilight is more relaxing' (Donald, Patient)

5.2.4 Haemodialysis Machines and other equipment

The unit requires a lot of equipment as it is used for every patient as part of their treatment.

The key piece of equipment is the haemodialysis machine. There are two types of machine used in the unit. Pictured in Figure 15 is the newer style machine, which is used by most patients. A few slightly older machines remain in the area but did not

appear to be used regularly and usually were only used when there were no newer machines available.



Figure 15: Haemodialysis Machine in use (newer style machine)

Haemodialysis machines are washed externally by the staff and the machine also goes through an internal ‘heat disinfection’. This occurs after each patient and takes around 40 minutes to complete.

The machines are usually positioned on the side of the chair where the patient’s vascular access is, so the haemodialysis lines do not lie across them when the machine is in use, as part of the local unit procedures.

All of the equipment needed for attaching someone on and off a dialysis machine, regardless of their vascular access, is contained in a trolley. This is used by staff and taken to each patient to be used as a counter top for opening the equipment (Figure 16).

The trolleys are also used by staff as part of the medication round, where the injection medication is put out on the top of the trolley and then pushed from patient to patient as the equipment needed is contained within the trolley. These are stocked

Perceptions and Experiences of Direct Patient Care
up by both the registered nurses and the healthcare support workers every shift.
Each room had four trolleys and they are all set up the same way.



Figure 16: The cannulation trolleys fully stocked and ready for use.



Figure 17: One patient waiting to go on machine

Figure 17 shows in the front of photograph a patient waiting for staff to assess, prepare and start haemodialysis treatment. In the rear of the photo, a registered nurse is commencing for another patient. The patient in the middle has already started treatment.

5.2.5 Alarms

Alarms from the machines broke the silence of the dialysis rooms at times, reminding staff to do things like checking blood pressures or to administer medication. Alarms also sounded when the machines had problems that needed to be checked. High or low pressures related to the blood being removed and returned to the patient. The machine would alarm due to these pressure changes and nursing staff would attend to the machine to check it. Occasionally, the patients would silence the alarms so the staff did not require to go over to the patient to silence the alarm if it was not required.

Each dialysis station in the unit had an alarm for the patients to use, similar to a nurse call button from an inpatient area. These were rarely used in the main room areas. However, the patients in the cubicle rooms would sometimes use them as they were in the smaller rooms, away from staff and behind a closed door.

If patients used the patient toilets (located just off the main corridor between the reception and the dialysis rooms) and activated the alarm, a light would appear on in all the dialysis rooms to alert staff, but the alarm would only sound in room 2, the closest room to the toilets.

5.2.6 Cleaning

Cleaning has the attention of nurses and clinical support workers whilst patients are in the unit receiving dialysis.

Cleaning matrix

The cleaning of the unit environment was part of the staff role. Some patients assisted with the cleaning and clearing of their area by removing their used linen from the chair and putting it in the linen buggy for the staff to then tie up.



Figure 18: Clinical Support Worker cleaning the now vacant dialysis space

Cleaning was seen to be a focus at different times, particularly in the afternoon, due to the increase of staff numbers with both shifts being present in the unit and also at the end of the day, during the twilight session, as certain tasks required to be completed by the end of each shift and before staff left the unit to go home.

When a patient completes treatment, there is at times a focus on getting the machine into its 'heat clean' as quickly as possible, so that the machine will be ready for the next patient. This is done by one member of staff focusing on the patient and the access, either the perm-cath or the fistula and needle removal, and another staff member removing the lines and cleaning the machine at the same time. When time is not as much of a priority, or there are not enough members of staff to undertake this activity, the staff sometimes leave the machine until the patient has had their needles removed and then the staff will turn their attention to the machine.

Cleaning was completed after a patient had vacated a dialysis space when the chair, machine and the surrounding area was cleaned and disinfected in preparation for the next patient.

5.2.7 Important Objects in the Unit

Within this particular haemodialysis unit, different objects had significance for the staff and patients and were referred to frequently by both these groups.

Clocks and Time

Each room had a clock in it, and the machines also have a clock face on them when in the 'sleep' mode, to indicate how much time is left of the treatment.

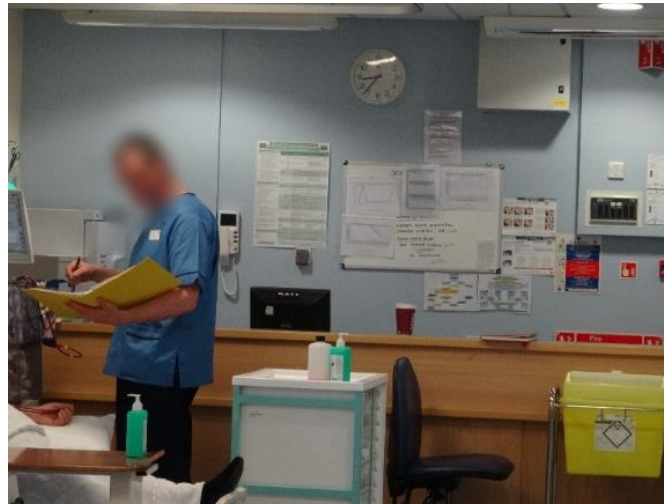


Figure 19: The clock above the desk in room 2

Time is important in this environment, as patients are keen to get on and off the machine as quickly as possible. Patients will ask, as they want to know what time they are on the machine or finishing treatment, or the actual time they have left to go. Staff will usually tell the patients, if they have not already asked, what time they will finish. Patients then call their families to tell them they are on the machine and what time they will be home.

Time is hugely important to some patients and staff, but some find seeing the time unhelpful during their treatment. Some patients found the focus on time very difficult, and felt it did not allow them to switch off, as they were always focused on it. One patient covered the clock on his patient television so he didn't see the time whilst on dialysis.

'But eh, it's really annoys me is the time. Ken what I mean..... that's why I've got that damn thing, I've got tape on it, naw I couldn't, that

would make it worse, if there was a clock there, ken what I mean, cause it was like that even working outside, if you looked round there was always a clock there, just have to switch yourself off, ken, but eh, I'm quite happy the way I get treated in here, they seem to keep you going sort-a style' (Bob, Patient)

The times that patients will be ready is collected and put on a board in the reception areas so that ambulance crews and volunteer drivers can plan taking people home following treatment.

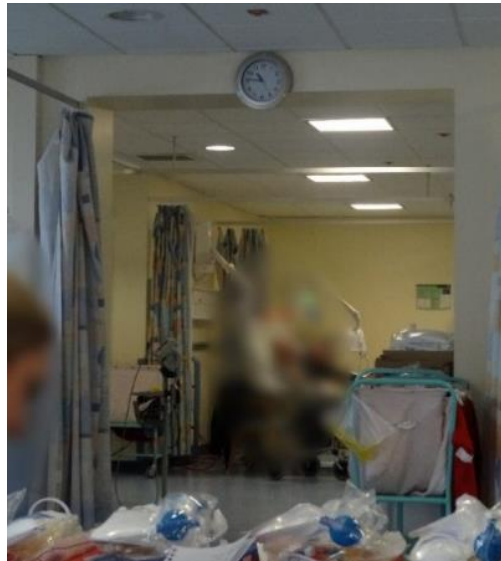


Figure 20: The room 4 clock in a prominent position

Knowing when patients would be off the machine allows for events to be planned, for example medical reviews. The staff would call the doctors, and tell them at what time the treatment would be finished, so that they knew how long they had before they would leave the unit.

This fieldnote highlights the importance of knowing what time it is for patients.

'What time does the clock say? I can't see cause of the light'

***The light from the ceiling is reflecting on the clock on the wall obscuring the time to the patient. The patient cannot move or adjust his position as he is attached to the machine with needles in his arm, but the clock and time appears to be important to him.*

Chatting with staff for patients, helps pass the time when patients are on dialysis.

'Chat about what people are up to on their days off, a little bit of conversation, makes the time go by' (Jerry, Patient)

Time was also important to staff, as they would construct a list of the finishing times for each patient to plan their workload. Having patients all coming off at the same time could be problematic, as they may not have enough staff available in the room to terminate treatment.

The Room List

For every shift or group of patients in each room, the staff will write a list with the patients, the time they are due to come off the machine and any medications they are prescribed (Figure 21). The list helps in the planning of the next shift and where patients should go and has the information in one place to see all patients at a glance.

The list of medications is a prompt for the staff to remind them who requires what, especially for the end of dialysis, as some are given during the 'wash back⁵' phase. The medications also need to be taken from the fridge in room 2 or from the drug cupboard in the treatment room, so the list can be used when collecting these medications.

[Obscured]	1145	N ₁₀
[Obscured]	12 ⁰⁰	N ₂ A ₁
[Obscured]	12 ¹⁰	U ₁₀₀ N ₈
[Obscured]	12 ¹⁰	V ₁₀₀ N ₅
[Obscured]	12 ³⁰	N ₆
[Obscured]	12 ³⁵	N ₆
[Obscured]	12 ⁵⁵	V ₁₀₀ N ₂ A ₂
[Obscured]	13 ¹⁰	- N ₁₀

Figure 21: One of the room lists

⁵Wash-back is part of the disconnection process, where the patients' blood is washed-back into the patient, so their blood does not remain in the machine.

Keys

The keys were frequently mentioned, searched for and used by both staff groups during the observations periods. ‘Who’s got the keys’ was a phrase expressed several times during an observation session, as the keys were usually with the nurse in charge of the shift but appeared difficult to track down.

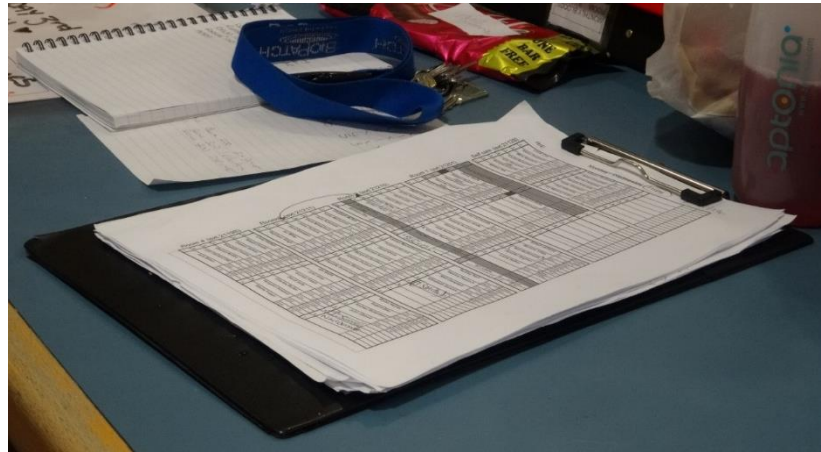


Figure 22: The keys and the main board

The keys, or ‘big bunch’ identified by blue lanyard was the main set of keys for the unit (See Figure 22). These are usually with the coordinating nurse, or as seen in Figure 22, on the desk in room 2. These keys had the drug cupboard keys and keys for the filing cabinets which contained the patients’ notes. A lot of medication is located in the drug cupboard, which is accessed with this bunch of keys, and is therefore required by staff on a regular basis.

On two occasions, patients actually responded to the question posed to the room by the nurse ‘who’s got the keys’, to say ‘they aren’t in here!’, and the second occasion ‘Sheila has them!’

Skill Mix

The skill mix is the week ahead allocation of staff on duty to the different rooms (Figure 23). This skill mix shows all staff on duty for the day, both day shift and twilight, to indicate quickly which staff are on duty and which rooms they will be working in.

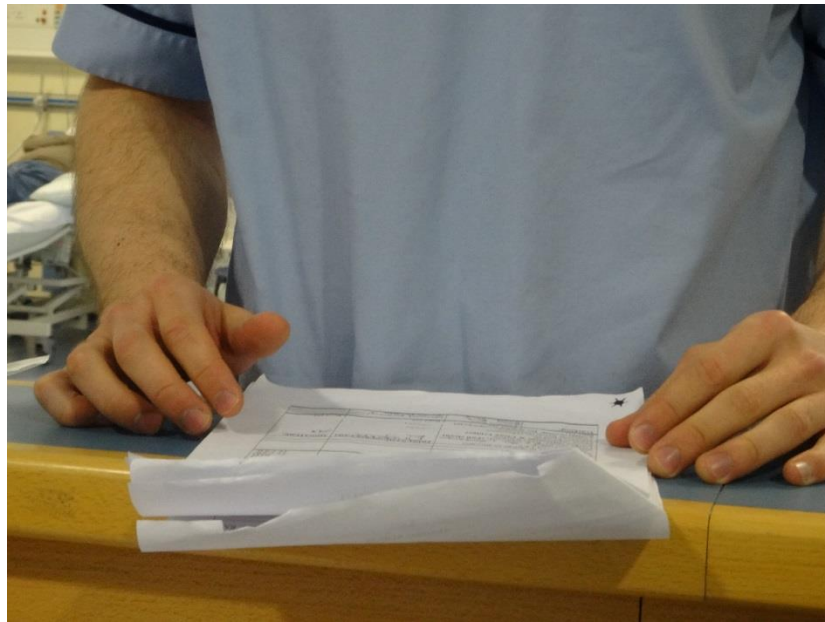


Figure 23: Looking at the skill mix

The skill mix is used by the coordinating nurse as a register to check all staff have turned up for their shift and keeps track of where staff are allocated to work.

The skill mix also has a record of jobs which require to be done every shift of on a particular day, and once these jobs are complete, this is signed off on the skill mix by the staff completing the task. Things like tidying the stock room or machine room and cleaning the ice-machine, which is the responsibility of all unit staff rather than one particular room's job allocation.

The Doctors' List

The list was a piece of paper which the nurse in charge of the shift, or coordinating nurse, would complete for the doctors with the jobs which required to be undertaken or notes for the shift handover.

The Main Board

This is a clipboard with the current week's and following week's patient allocation and plan of haemodialysis spaces (shown in Figure 22). The main board allows for the staff to see at a glance the patients due to come in for treatment and would also indicate spaces which could be utilised by inpatients.

The main board is a master copy of the spaces and patients for that week. If patients were attending at a different time than normal, or patients from the ward or other areas were receiving treatment in this unit, their name would be allocated to a space on this 'board'.

The main board is an object of considerable focus for all staff, both nurses and support workers, during a shift. Staff will be crowded round it discussing the plan for the incoming group of patients and allocating spaces and workload while patients are on dialysis.

5.3 The Unit Staff

Within this particular main haemodialysis out-patient unit, there are two senior charge nurses, sometimes called band 7's or the Unit Sisters. Within the main dialysis unit there are also five deputy charge nurses (DCN) who are on band 6 level, with another two located at the two satellite units. There are over 60 other registered nurses at band 5 staff nurse level and nine healthcare support workers based in the main unit, however these staff can rotate out to the two local satellite units, and staff normally located in these satellite units would swap and work within the main unit.

Uniform colours help to distinguish between some of the roles. The band 7 Charge Nurses wear navy blue tunics, the band 6's and 5's wear cornflower blue tunics and the healthcare support workers wear pale-sky blue tunics, in line with the national uniform across all healthcare settings.

One patient highlighted that the uniforms helped him identify who did what. In this particular situation, one member of staff began his nursing training and started to wear a student uniform instead of his clinical support worker uniform.

'The first day I did come in here, Craig was on, in a light blue smock, the next day he came in he was in his student smock, he was showing his competence, taking me off my line, and my brain hadn't resolved that the student was working unattended, that was really off-putting, until I established that he was quite experienced' (Jerry, Patient)

The change of uniform was noticed by the patient, and did not understand why a student would be working as a member of staff unattended.

One satellite unit is run by another band 7 charge nurse and the staff in this particular unit do not rotate to this main renal unit, as it is part of another NHS Trust.

From this main unit, nursing staff also rotate to the renal and transplant inpatient areas within the hospital. When staff are rotated out to these areas, staff from these inpatient areas rotate into the unit to learn how to do haemodialysis. When staff, both registered nurses and healthcare support workers, are new to the area and are learning about dialysis, they get a supernumerary period where they shadow and work with a designated member of staff to support their learning and development.

In the haemodialysis unit, there were three main groups of staff identified through the research- the registered nurses, the clinical support workers and the medical staff (who were not included as participants in the study). There were also other external people who visited the unit but they did not feature prominently e.g. social workers or dieticians, and are not part of the study.

'It took me a while to work out, who was the nursing staff and who was the support workers' (Martha, Patient)

The clinical support workers and the registered nurses work very closely together, and both undertake some similar tasks or activities for patients. The two groups wear different uniforms, but can both deliver some aspects of haemodialysis care, like measuring blood pressure and weight, lining and priming the machines, assisting in the connection and disconnection and also in the removal of needles.

'If they were all in scrubs, you probably wouldn't know who was who, by what they do, I think there is lot of overlap in the roles' (Donald, Patient)

5.3.1 Co-ordinating Nurse

The co-ordinating nurse or the 'Nurse in Charge' (Figure 24) is seen holding the keys, the main board and doctors list.

The doctors' list, main board, and the skill mix are important objects and are usually held with the coordinating nurse, or nurse in charge of that particular shift, which can be either a band 6 charge nurse or a senior band 5 staff nurse.



Figure 24: The Nurse in Charge, coordinating the shift

It is important at times for the patients to be able to identify the nurse in charge of the shift, but the quote from one patient highlights that the patients are aware of this different position.

'Pick the nurses in charge, now that they are easily identified with the yellow badge, it's easier to work out who is in charge, but it was a good game to begin with, you could see some people were acting up, and that was interesting to see who was acting up, with the conversations they were having, who's got the board etc.' (Jerry, Patient)

5.3.2 Registered Nursing Staff

In the dialysis unit, there would be two registered nurses allocated to each room per shift, so in the afternoon crossover period there could be 4 registered nurses, and potentially more if there are new staff to the area in their supernumerary status.

'Professionalism, caring, good knowledge and understanding, - when people come here the key needs to be to gather as much knowledge as possible, and build on that knowledge cause things change' (Charlie, Registered Nurse)

Patients identified the registered nurses to be a crucial part of their dialysis treatment and a way of gaining information and support with the treatment.

'The hard work and tenacity of the staff- they just kept sayin' we'll try this, we'll try that' (Martha, Patient)

'Any nurse that was there, I would ask them, definitely, that's what they are here for aren't they?!' (Judy, Patient)

One nurse mentioned that one aspect of their role is to maintain a professional role and appearance to the patients, to allow them to be there for the patients.

'Some days have an element of acting, because let's face it, some days you know you are not tip top and you have to rely on you to be tip top so if they are asking how I am, I'm always great, always fine, which is good, and so I find that quite easy' (Darcy, Registered Nurse)



Figure 25: Staff Nurse

Figure 25 shows a staff nurse in the cornflower blue coloured tunic. This is the regulation colour for all registered nurses to wear.

5.3.3 Aspects of Haemodialysis Nursing

The nurses are seen to be in charge of the dialysis and have the knowledge and skills to facilitate this.

Having the knowledge and expertise

The nurses are viewed as having a lot of knowledge and experience in haemodialysis and patients believe they know what they are doing and trust them.

'You have to remember these are skilled individuals, they haven't walked in off the street and handed a set of needles and told to sort it out! (Jerry, Patient)

Donald identified that he would wait for the registered nurses as they knew about dialysis and could give patients the information they wanted.

'Generally, I would wait for the nurses' (Donald, Patient)

The nurses acknowledge that some patients are happy for them to make the decisions and that patients do not always want to engage in the decision making or discussion about their treatment.

'I would say the majority of patients are quite happy to leave it in your hands' (Jan, Registered Nurse)

With this knowledge, the staff do require to tell and encourage patients to take more control of their treatment and restrictions. Nurses would highlight to patients when patients needed to do something and be more aware.

Taken from Observation session 4

One nurse is telling the patient that he needs to really watch his fluid intake, the patient has come in 5 litres over, 'we can't take that off during your treatment', would you stay longer and do some isolated UF? You shouldn't stay this much over, it's not good for you.

The nurse here was trying to get the patient to engage in their treatment and fluid gains.

This was also highlighted in the interviews, with staff identifying that they do have to tell patients to be more involved in the decisions about treatment. Dani had concerns about a patient whose weight kept fluctuating and staff were not always identifying if there was fluid to be removed.

'We have told him to tell the staff if his weights gone up or down or the fluid isn't there' (Dani, Registered Nurse)

Being in charge of treatment

The patients acknowledge and approve of the staff having the control of their treatment and care.

'The control of what happens is dictated by doctors, nurses, I don't want to be in control as much as lining the machine and putting my

needles in, I have trust and confidence in people to do that, (Rita, Patient)

The staff also highlight that they are in charge of the treatment, and remark that the patients trust them to provide good care and treatment.

'You are giving them a good standard of care' (Jan, Registered Nurse)

Sometimes, as the staff have this expert knowledge they do not involve or will contradict treatment plans or advice from patients. Some staff do this- by 'trumping' them with procedures or rules as highlighted by one patient in his experience.

'One or two of the senior people, they are extremely focused, don't have much latitude, stick to the procedures, slightly over reacting to certain situations cause they don't know the, they are coming in and making an immediate robotic decision on your care' (Jerry, Patient)

5.3.4 Healthcare Support Workers

Healthcare support workers, or clinical support workers, are the unregistered nursing staff who work in the unit.

The healthcare support workers in this specialised area identified themselves as doing a different job from the registered nurses.

Observation 19

'I can't give drugs or anything like that' (Rachel, Support Worker)

**taken from fieldnotes as part of an informal conversation*

From an informal chat, the healthcare support workers did feel different to the registered nurses, and highlighting this was the above quote, during an informal conversation as part of an observation session, highlighting there is a difference in some aspects of their role from the registered nurse.

The support workers in the dialysis unit have a role which assists the registered nursing staff and the patients, whilst also having some autonomous aspects to their

Perceptions and Experiences of Direct Patient Care role. A support worker is assigned a room, just as the registered nursing staff are, and are expected to assist the patients and the care that goes on within that room.

Historically, these support workers were machine technicians, who primarily looked after the machine and then over time the role changed to include a significant nursing and patient care focus, rather than only technical support.

This job or position is referred to at times, by both staff and patients, as ‘techs’, particularly by some of the staff who have been in the unit for a long time. The patients, both old and new, also use this term on occasion.

This group of staff are more than just helpers within this unit and the registered nurses and patients view them as important in this area.

‘They are not just there to give tea and toast’ (Edward, Patient)

The patients view the support worker staff to be more than doing the refreshments and food, they are important to the patients.



Figure 26: Support Worker handing out tea and sandwiches

The support workers are viewed as important and assist the patients when coming for treatment.

‘They are always friendly, and willing to do anything (Rita, Patient)

Patients identified that some tasks support workers were able to do as well as the registered nurses.

'The support workers are there, they are differently skilled, they won't put you on but they can take you off (dialysis)' (Jerry, Patient)



Figure 27: A support worker removing needles from a fistula

Figure 27 shows a support worker who is assisting in taking a patient off dialysis. They are wearing personal protective equipment (a visor, gloves and a plastic apron) and as part of this process, removing the tapes, needles and then holding the fistula.

One registered nurse acknowledged the healthcare support workers as an important part of patient care, but that they do have a limit to how much they will do, especially when it comes to gathering information and asking questions.

'The support workers do give care, and I've seen it, they do talk with the patients and interact with them. But I don't know if they give the same... they'll ask them how they are but won't dig any further, we'll go in deeper' (Angie, Registered Nurse)

One support worker detailed a situation where a patient was asking them questions about transplantation.

'There were some questions which I felt I could answer' (Lewis, Support Worker)

There were other questions where they suggested that the patient speak with the nurse or the transplant team, as this was something they felt they could not comment

on, but identified that they needed to get advice from the appropriate people who had access to that information.

The support workers are aware of their role limitations and also when they have the knowledge and can adequately inform their patients.

The patients identified that the support workers do have experience and knowledge on aspects of haemodialysis, and they do listen to them about these things.

'When they taking your blood pressure, or if they are taking the blood pressure and it's a bit low...you will listen to them cause' they have experience with that' (Rita, Patient)

Some patients identified that the support workers may not have the information on some aspects, but were knowledgeable on aspects such as the haemodialysis machine.

'You wouldn't put medical questions to them, but maybe with some of the machine problems, maybe asking what does this mean- ...they are there, they know about the machine, because that's what they are there for as well' (Emma, Patient)

Donald identified that he had worked out that one of support workers did know about different aspects of treatment and haemodialysis.

'Well there was a support worker who seemed very good, so I was asking her things and she seemed to know' (Donald, Patient)

The patients identified that the support workers do have experience and knowledge on aspects of haemodialysis, and they do listen to them about certain aspects of dialysis.

'If anything goes wrong with the machine, it's the support workers, don't get me wrong the staff do do it, but if there is anything great wrong it's the support workers who come' (Rita, Patient)

The support workers did feel able to provide emotional care, not just clinical care and expertise in the haemodialysis unit. They do provide emotional support to patients, and find certain aspects of haemodialysis difficult.

'I struggle watching him in pain, I find that distressing to watch, it happens every day I am in there, so anything I can do to alleviate that kind of stuff, I can't give drugs or anything like that, but even if it's just sitting down and showing that you actually care about that kind of thing, and just saying 'I'm sorry to hear that. Or what is the plan, or what have they been saying about your problem' (Jo, Support Worker)

Billie, a support worker, viewed part of their role was to provide patient care and comfort to patients. They also felt that this was not viewed by both patients and registered nurses as part of the role they carried out in the unit.

'I think as a support worker people don't think that we care, I think people just think that we are there to line machines and do the techy side of things, but actually we do care, and I care if a patient's not well and things like that, and I find myself, I want to go to them. I want to make sure they are well, they are happy' (Billie, Support Worker)

This was also highlighted by a comment from one of the registered nurses, that the support workers did not provide as much patient care as the registered nurses.

'Nurses do more patient care, than the support workers, we use them as technicians, for more technical machine aspects and they help get patients on and off, but they quite often disappear to do other things like stocking up or the lines, things that don't really affect the patient on a day to day basis' (Jan, Registered Nurse)

This highlights the difference in roles, and that the registered nurses do use the support workers for certain jobs which are less patient care related.

*****The support workers are here, they are on shift, but they don't spend a lot of time in the room in the presence of the patient, at the moment, the support worker has left the room 'I'm doing the teas' so for 15-20 minutes the patients are alone in the room with one nurse, the support worker is making the teas and then working their way round the unit handing out the tea and toast, until they end up in this room to provide to this lot of patients, they then leave again to go and clean up the trolley and kitchen- so not available to care or support patients in this time, but providing something very vital***

This particular entry from the researchers fieldnotes and field diary also demonstrates the difference in roles and duties when the patients are on haemodialysis.

There was also a difference for the nurse, between them and the support workers as one nurse identified.

'They (clinical support workers) take the time, they aren't rushed'
(Charlie, Registered Nurse)

The support workers not being rushed because of their different role and the job they do in the unit was seen as a positive aspect for patients and the unit.

5.3.5 Differences between Staff

There were differences in the staff who worked in the unit, and patients could identify these differences during the interviews.

Whilst care was viewed by patients as a positive thing, and patients mentioned that everything is great, there were still some comments which highlighted the differences between staff and care delivery/time with staff.

Patients commented that staff were different and did things in different ways.

Staff who were able to put patients on the machine and chat at the same time was seen as a positive aspect.

'It's nice when the ones are more relaxed will chat to you, while they are doing it, it does make you feel more confident that they know what they are doing, they don't seem nervous when they are doing it'
(Donald, Patient)

Some staff would be happy to explain or answer questions.

*'I like information and **most people** are happy to explain whenever I have questions'* (Jerry, Patient)

Some patients identified that some staff were more suited to spending time with patients than others.

'Some people are more people persons' (Rita, Patient)

Staff were focused on chatting and spending time with patients in this way.

'I like talking to staff, and some are more chatty' (Jerry, Patient)

Some registered nurses were viewed as being more factual in their care delivery, which was viewed as both positive and negative by the patients.

'They are clinical robots for a reason, because they are following procedure that has care at the heart of it, then there is not much negotiation, you are still getting cared for' (Jerry, Patient)

'The nurse I had was matter of fact' (Judy, Patient)

Staff identified that they worked in the unit differently and carried out their duties in different ways.

'A lot of people just sit at the desk' (Jan, Registered Nurse)

5.3.6 Doctors

Despite medical staff not being active participants in the observations, they are alluded to by both the nursing staff and patients in the unit and feature in the interview data.

Within this particular dialysis unit during the research there were two male staff grade doctors who work within the unit, out-of-hours medical staff and the hospital at night team cover the unit from the renal ward. Renal Consultant physicians visit the patients in the unit as well as seeing them during external clinic appointments.

Patients are still aware of the importance of medical staff and this is a limitation of the nurses' role/ability to provide 'care' as information provision.

Patients have suggested that the doctors are still crucial in providing care through information, which the nurses can do, but ultimately it lies with the doctors.

Highlighting the importance of this role, and the patients still value having medical presence, and contact time with them rather than with the nurses.

'I would ask to see the doctor, because basically they are the ones who answer the questions health wise, you can't expect a nurse to know everything' (Emma, Patient)

5.4 Patients in the Haemodialysis Unit

In this particular dialysis unit, patients are mostly out-patients, however, some patients may attend as in-patients within the hospital. The unit is the main unit, with some patients from these units attend here, due to not being 'fit enough' for a satellite unit with less medical cover, or due to requiring services which are located at the main unit e.g. vascular access nurses or scanning equipment.



Figure 28: A patient on dialysis reading their e-book

There can be up to 38 patients during a shift, with three shifts in a day, leading to, at times, over 100 patients attending the unit in the day. They were a mix of patients, both young and old and male and female across all shifts.

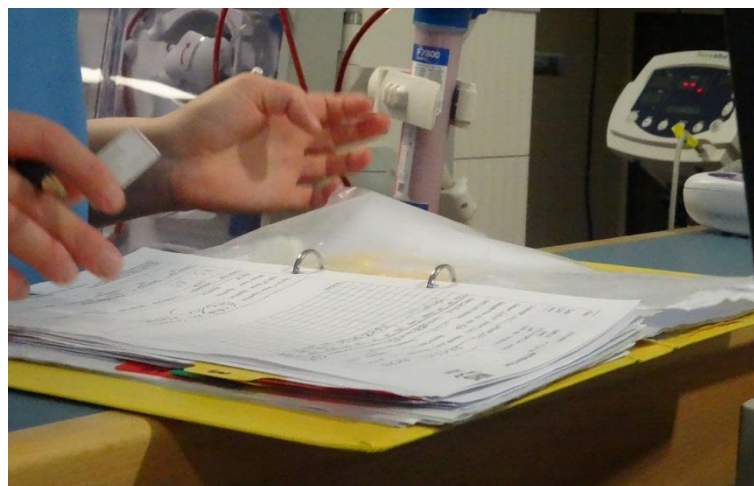


Figure 29: Patient Folder with their haemodialysis information

Each patient has their own folder with their prescription and dialysis information in it, they are at times colour coded, relating to which shift they are on or the type of haemodialysis they get.

Through the research, different aspects were identified relating to the patients, their identity and emotions relating to dialysis and having kidney disease. These will be explored in this section.

Patients watch other patients and learn from each other about treatment or how things work in the unit.

‘Observe and think oh well I can do that and chat like that’ (Sandra, Patient)

5.4.1 Patients’ identity

Patients did at times refer to themselves in certain ways to identify their belonging to the unit. Being from the ward area meant a different thing, and had an impact on their treatment.

Within the out-patient area and as part of being a haemodialysis patient, the patients refer to themselves as in-patients or out-patients and highlighted the differences between these positions or statuses. Patients and nursing staff also would be able to identify others who were in these different categories, and this did have a bearing on the care they required and experienced.

Patients felt in the dialysis unit that there was a difference in how they were treated. There was a difference in the care and experience when this patient visited from the ward area as an in-patient, compared to as an out-patient.

‘You were just a ward patient’ (Jerry, Patient)

Being viewed as only a ward patient had a negative impact on their dialysis time and care experience.

‘I wasn’t being treated as an outpatient’ (Jerry, Patient)

Staff also identified that patients are identified differently if they are in-patients or out-patients due to this status. Staff acknowledged that out-patients are generally ‘fitter’ or ‘well’

‘They are outpatients and quite well’ (Marty, Registered Nurse)

Staff also acknowledged that patients reacted to them differently due to their status being different.

One of the support workers acknowledged that the patients who are out-patients deal with dialysis treatment and the staff differently.

‘When they’re in the ward sometimes they share a wee bit more when they’re in that particular state whereas (in dialysis) they’ve got that armour built back up again, they’ve got their brick walls up’ (Lee Registered Nurse)

Betty describes other patients, other out-patients, who also treat staff differently, who they blame for feeling unwell during treatment.

‘Then you can watch other patients and they’re angry gits, they are taking out on the nurses like it’s they’re fault that you’ve cramp. That you have a headache, your blood pressure’s dropping. Some patients aren’t as patient (Betty, Patient)

5.4.2 Understanding their Treatment and Kidney Disease

Patients during the interviews identified knowledge of their treatment as something which they develop through their continued attendance for dialysis.

The staff, both registered nurses and support workers, are able to assist and provide education on dialysis, but patients do identify that they will not be as ‘good’ as the nurses in understanding dialysis.

‘I don’t think I will ever know more than them (nurses)’ (Rita, Patient)

Patients will ask staff for answers or to explain things, sometimes for a second or third time.

'There's still a lot I don't understand but they are always willing for if I do have questions, even if I've asked them about 10 times' (Martha, Patient)

'If you want to know anything, ask the nurse, they know more than anything, I think they know more than the doctors!' (Sandra Patient)

Learning appears to be mostly patient-led and predominantly down to the patients asking questions.

'Over time, I feel I have only learned things through osmosis, just listening, and thinking' (Donald, Patient)

Patients identified that they were not able to learn as well until they were in the unit and part of what was going on.

'Until you are actually doing it, you don't take it in' (Donald, Patient)

The staff in the unit understand that patients do not always understand or have expectations about their treatment which can impact on their dialysis experience.

'Cause I think sometimes their expectations are completely different from what it's like, so sometimes just talking them through it' (Dani, Registered Nurse)

Having Knowledge and Expertise

Patients do have expert knowledge and are at times very involved and demonstrate their knowledge during treatment.

Julia, the staff nurse picks out the tinzaparin from the middle drawer of the cannulation trolley, it's a blue one. 'I normally get a green one' Steve (the patient), she puts it back in the drawer and gets out a green one.

****The different dosages are different colours.*

This fieldnote selection shows the knowledge the patient has who corrects the nurse as she has taken out the wrong colour and dose of anticoagulation (tinzaparin) from the trolley when preparing the equipment to go on the machine. This highlights the awareness the patient has of their treatment and their normal process.

5.4.3 Having to start haemodialysis

Beginning dialysis is known to be a difficult period for patients. Patients talked about beginning dialysis and how they didn't know what would happen.

'It was felt that I would know what was expected of me when I came in, and of course I had no idea (Donald, Patient)

Donald here describes the staff assuming that he knew what would happen in dialysis and also that because he didn't know what to ask, he was unable to get information.

5.4.4 Requirement to have dialysis

Having to come for treatment was challenging for patients.

'There are some days where you sit here ... really, I'm coming here again' (Jerry, Patient)

'I've got to get it done, shift yourself get out the door and get there' (Judy, Patient)

Patients identified that despite it being hard, they knew they had to come.

'You've got to do it' (Edward, Patient)

'Can't let it bother me, just got to get on with it' (Bob, Patient)

Despite not wanting to attend, patients knew if they did not get treatment then there would be consequences.

'You've just got to say well it is saving my life and just go to work, keep thinking but sometimes it's hard, just can't do it, canny do it, you get there, it's a struggle at times' (Barbara, Patient)

'If I want to live I have to do it, no choice' (Judy, Patient)

'It's nobody's fault we are here (on dialysis), it's just circumstance and that's it' (Emma, Patient)

Staff identified that some patients do just appear to get on with treatment and come in every session as planned.

'He's never complained, he's never missed dialysis' (Dani, Registered Nurse)

5.4.5 Becoming like ‘everyone else’

There is a change in patients due to attending for treatment. When Donald first started, he noticed patients ‘itching to get on’, and he did not understand why they felt like this.

However,

‘I’m now the same, can you get me on, can you get me on as soon as possible, before I would just sit and wait to be called, and then no-one would come and they’d say oh you should of just come through! I wanted to sit and wait, but now when you’ve been doing it for a little while, you think I’m getting in as soon as possible and getting off as soon as possible. I didn’t think I’d be like that, but you just fit in with everyone else’ (Donald, Patient)

Donald here shows that he has adjusted and changed his thoughts about haemodialysis and the important aspects and become similar to the other patients.

5.4.6 Emotions

Patients mentioned being scared or terrified when facing dialysis.

‘The thought of having this done three times a week was terrifying’ (Donald, Patient)

Patients were frustrated with having to come for treatment and did not think others could understand what it was like.

‘They say what’s wrong with you? I say that blasted machine! Four hours of that, being stuck on here, how would you like it?’ (Phil, Patient)

During treatment, Martha was unable to sleep or do something with her time. She was frustrated she couldn’t switch off when on dialysis.

‘Everyone else was sitting around and reading, and watching TV and having a doze, and I was thinking why me!’ (Martha, Patient)

Barbara felt that the nurses didn’t see how the patients felt about being on dialysis, and she was not used to it after a year attending the unit.

'I'm still coming to terms with it, even after a year, it gets you down, you can sort of feel, you sort of think I can't do this anymore, although the nurses don't see that side of it' (Barbara, Patient)

5.4.7 Coping

Patients identified that time with staff can help them cope with dialysis, both when initially starting treatment and also when things were tough and difficult.

'I thought looking back when I first got on dialysis it would be grand if I could speak to someone, someone not so much the psychiatrist, but this is what your life is going to be, it's up to you how to spend it, you can still have a good life, but you have to cut back on certain things, essential to stick to the diet' (Edward, Patient)

'There have been times when I have spoken to the nurses if I'm feeling low, or a bit depressed' (Martha, Patient)

5.4.8 How patients deal with their treatment

Dealing with treatment was seen in different ways, and some patients did not discuss or process their treatment with the staff in the unit. Some patients treated their treatment as part of a job or obligation.

'I look at it when I go on dialysis as a part-time job, so many days a week, just get on with it, and normally in a way you have two lives, out with dialysis and in dialysis, although you get on well with other patients you don't socialise with other patients, which is understandable, try and have your ordinary life when you are not on the machine' (Edward, Patient)

As some patients did not always engage with the staff or treatment, it was a challenge for staff to deal with this disengagement behaviour.

'They (patients) are just not interested in what you have to say, they just want to come in, get their needles in, have their treatment and go home. And anything that happens in between they aren't bothered as long as you deal with it' (Jan, Registered Nurse)

Not being interested in their treatment was something which was identified and witnessed in the unit. Patients did not always appear to be engaging with staff when they were trying to discuss challenges with treatment or diet and fluid restrictions and other patients identified the difference in patients who did engage or not.

'Quite a few people don't care about their treatment' (Jerry, Patient)

5.4.9 Visitors or Relatives in the unit

The haemodialysis unit allowed visitors to the unit, except during the busy periods when patients were getting put on or taken off dialysis. During the fieldwork, there was only one time which a patient had visitors in the haemodialysis unit.

Patients identified that sometimes they did not want visitors to be part of their dialysis experience.

'A couple of times, in the old hospital, and I think my sister once from Canada saw me, but I think, erm., that may be helpful to some, help the time to pass, but normally I say no' (Edward, Patient)

5.5 Rhythm of Haemodialysis

In the dialysis unit, there is a rhythm or routine to the care and processes which occur. There were busy periods when patients are arriving and being put on dialysis, and then things become slower paced and quieter once this has occurred. Things then become busy again when the patients are finishing treatment and coming off the machine, and the room is getting prepared for the next group and shift of patients to arrive. The cycle then repeats, with patients arriving and lots of activity from staff.

The different phases or aspects to haemodialysis care are identified in the following section. The care and time with nursing staff can be dependent on the time of day and what things are occurring within the haemodialysis room and the wider unit.

5.5.1 Pattern or Routine of Haemodialysis Treatment

During a usual or typical shift, there are different phases of busy and active times for staff and patients and then identifiable quieter periods when patients are in the unit. The typical pattern or routine to the haemodialysis process is explained here, to understand the routine in this unit.

Patient arrival to the Unit

Patients arrive at the unit and wait in the waiting room until the staff call them into the appropriate room. Some patients provide their own transport or use public transport to get them to and from the unit.

Others who qualify are able to get patient transport. This is organised by the ward clerk who usually sits behind the desk at reception. This transport can be an ambulance, a volunteer driver or a taxi. Patients share transport as much as possible so usually travel to and from the unit in this provided transport with the same small group of patients.

'Sit in the waiting room a while, that's normal, but once you come through there is someone waiting to put you on' (Sandra, Patient)

The waiting in the waiting area to be called through is a difficult part of the routine for patients. This is especially true for the afternoon and twilight shifts, as these patients require to wait for the appointment time, as the machines will not be ready before this time due to patients having been on the machine already; it takes 40 minutes for the machine to go through the heat cleaning cycle.

Donald here identifies that he has become very focused on getting in and on the machine, and then off as quickly as possible. He highlights here that this was something that was not important in the beginning but is now something he values highly.

'I just want to get on the machine as soon as I get in You just got to get on and be away sort of style' (Bob, Patient)

Commencement of Dialysis

Once a patient is on haemodialysis, an important aspect identified as part of the care and routine is to make sure the patient has everything they should need when receiving treatment. This could be providing them with a blanket or sheet to cover them, if this wasn't provided prior to their attachment to the machine, or medication that they take at the start of treatment, which can help with some symptoms of kidney failure e.g. quinine sulphate for cramps and Chlorphenamine for itching.

'I think that makes them happy, I think they like to be all set' (Charlene, Registered Nurse)

Betty described that when she was on dialysis it was difficult to think about anything else, she could only think about dialysis and treatment.

'All your focus for what's out there is absolute zero' (Betty, Patient)

The routine of treatment for staff can sometimes be

‘Putting them on then leaving them’ (Charlene, Registered Nurse)

Depending on what else needs to be done and the patient’s needs, the next time staff may really interact with them could be in the coming off period of treatment.

When putting patients on the machine and starting dialysis, staff identified that they required to communicate during this period as well as attaching the patient to the machine.

‘Just having a bit of chat, before they actually go on the machine- instead of just attaching them up and treating them like dummies’ (Jan, Registered Nurse)

The patients know the staff will come and go with them and different aspects of their treatment.

‘But then they give me an injection, then they go away then they come back (Phil, Patient)

The Lull

The period in which everyone is on the machine is referred to by some staff as the lull, and patients have identified this period as a part of their dialysis care and routine.

The interdialysis phase, described as the lull by unit staff, when all the patients are on the machines, and staff are waiting for the patients to come off.

This is a time where sometimes more active/engaged care can take place, however not for all and not for the whole time.

There will always be other unit activities which take place in this space e.g. staff breaks, so there are fewer staff to provide care, do cleaning or stocking up.

‘The lull in between, after everyone is on and the notes are written... a lot of staff shy away from the tasks to be done, hoping someone else will do it instead’ (Jan, Registered Nurse)

The Lull is viewed by some as the quiet or down time in the unit.

'In that spare hour from 4-5pm, when it's really quiet' (Angie, Registered Nurse)

Patients spend this time doing different things depending on how the treatment is going and how they are feeling.

'I can read my paper, and I have my tablet, and I have games on it I could play, I can read, I've got books on it, I've got music on it, so I think probably I like a variety of things, sometimes I have a doze, I prefer doing that, and I've only got one hand, so I can't do cross stitch any more' (Rita, Patient)

'If I get fed up I just put my TV on, or play that (points to phone)' (Judy, Patient)

'I just have it for company' (Phil, Patient)

This comment from Phil (Patient) watching the TV during dialysis highlights the lack of company in the unit and that the TV provides this for him. Registered nurses, support workers and other staff groups who visit the unit do not solely provide company to the patients during the entire duration of treatment. The staff spent time with the patients but there were other requirements during a shift, and as there are only two or three staff members in a room with up to eight patients, work was shared amongst the staff group.



Figure 30: Patient watching TV whilst on haemodialysis

Observation 2

*****patients are on the machine, reading, using puzzle books, reading, iPad, headphones and TV or DVD's, they are piled up on the patient table in front of them, computers, playing computer games- solitaire, sleeping,***

This excerpt from the fieldnotes depicts the variety of ways patients can spend this lull time. Patients have done marking, or college work whilst on dialysis, and use their time on the machine and in dialysis as part of their weekly routine for working.

Observation 4

*****Music from laptop, their phones ringing, at times I can't hear what the staff are saying, or the patients are saying to them due to the noises- or is that what they want, to be drowned out?***



Figure 31: Patient reading the newspaper whilst on dialysis

By reading the newspaper the patient is distracted, coping, using the time as part of his or her daily routine. The use of the newspaper also relegates staff to be in a passive role for the patient, as the use of the newspaper does not require them.

Figure 32 shows a patient lying back during treatment while they cover their eyes with an eye mask.



Figure 32: Patient lying back during dialysis

The lull can be a period of low activity, and when this happens staff then have the option to engage with patients and become more active.

'I would return (to the patient) in a period of low activity, have another little chat, engage with them again, maybe look as if I was engaging with everyone else, and just wander round' (Darcy, Registered Nurse)

The lull can also be when the staff spend time at the desk doing paperwork, and catching up with jobs from the previous group of patients, cleaning or planning the next shift (figure 33).

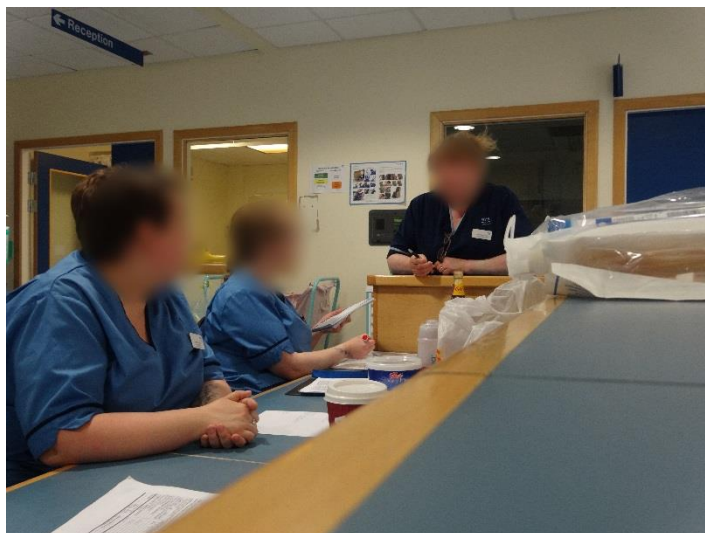


Figure 33: Nursing Staff during the 'lull' at the desk

All the 'work' is done, with the patients all on the machine, and the lines ready for the next shift. This picture demonstrates the staff behind the desk and not engaging with the patients during this 'lull' period.

Going Home

At some point during the shift, the staff will put things out on the patient table or put items out on top of the trolley as part of preparing for the patients to come off the machine.

The period where patients are coming off the machine is again quite hectic and busy, with staff moving round from patient to patient taking them off, depending on their finish time. The healthcare support workers and the registered nurses can discontinue dialysis which is using a fistula and needles, and the healthcare support workers can do the machine side of a discontinuation with a permcath.

The patients usually hold their own fistula sites where the needles come out. The recommendation is to hold for at least 10 minutes, some patients do less and some do more.

The patients get their blood pressure taken before they stand up from the chair, in case they have hypotension or low blood pressure.

The patients will then go and weigh themselves at the scales in the main corridor, while the staff are usually stripping the chair and machine area and washing them down to be prepared for the next patient. The patients return to the room with their weight, which is noted down in the notes by staff before then leaving the unit.

Ready for the Next shift

The machine and chair are washed, and new sheets and pillowcases are put in place. The machine is lined for the next patient and the next patient's folder is placed on top of the machine. Some staff will get the trolleys with equipment set up for some patients prior to their arrival to speed up the process.

5.5.2 Waiting

Waiting is a common feeling for haemodialysis patients. Patients wait in different ways. They will wait in the waiting room for the staff and machine to be ready for her to start treatment. Patients usually wait in the waiting room rather than in the dialysis unit, and then are invited through. Once they are on, they then wait for the end of treatment.

'It is important to get in and get on, it is, because the likes of this morning, I'm in the likes of 7am, so that's if, getting taken in at 8am, that's an hour, just sitting, waiting, you know' (Barbara, Patient)

Observation 7

'it will only be a minute' nurse says to patient as he stands at the entrance to the room - waiting on the machine to be ready.

***Staff acknowledge the waiting for the machine, and what is happening.*

Patients have to wait on the machine to be ready, or the space to be ready, and then for the treatment to finish and then transport to arrive. Staff sometimes have to wait for the patients to arrive, as machines may be ready before patients arrive for the appointment time.

Some patients also described the waiting for a kidney transplant as part of the dialysis experience

'Terrible you have to wait for someone to die to get a kidney' (Judy, Patient)

'Waiting on a transplant, it's something to look forward to' (Edward, Patient)

'And I'm now just waiting for my transplant' (Barbara, Patient)

Not all dialysis patients in the unit and who participated in the study were on the transplant waiting list.

5.5.3 Regularity of Care / Haemodialysis

This theme suggests there is a pattern or routine to the care delivery and processes. Staff and patients know what is going to happen during the time in dialysis, give or take a few emergency situations, but they know when breaks are, when staff start or finish, they know what time the food trolley is, when checks are done. Both groups know the routine, and also use the routine to help cope with the dialysis. They also know the pattern of events like going on the machine, checks happen during treatment and then they come off. Some patients arrive slightly later than others, or are always the first or last to go on the machine due to preference or transport. The shortest hours of treatment are normally the last to go on.

There is a regularity of the care or processes seen through the observations and identified by patients and staff. The same tasks or activities occur in the unit despite the patient group or needs. Also, the time spent by staff with patients is noticed at predictable points during their treatment and within the time patients are in the unit.

'For the goings on is the same really, whether its twilight or afternoon' (Donald, Patient)

The patients usually arrive, get their blood pressure and weight checked and then will be connected to the machine and dialysis commenced. Things occur during the treatment like checks and monitoring, and drug administration and then patients will be discontinued from treatment at the end of the prescribed dialysis time.

'Me I just want to get on the machine as soon as I get in, I've hate sitting through there, but it's like everything else it can't be helped' (Bob, Patient)

The care plans, which are used on a daily basis have assisted in the routine and checking certain aspects for patients each time they come to the unit for treatment.

'Everyone pretty much has the same routine, cause you are working off the form, you know, so there are questions that have to be asked' (Jerry, Patient)

5.5.4 Prioritisation of Care

There is a prioritisation and organisation of care within the haemodialysis unit with which both patients and staff are involved and understand.

Shared prioritisation between patients and staff happened when emergency situations occurred and people were not well in the unit. Other jobs or patients would not be prioritised, and the unwell patient would be the focus for the staff in that room, and potentially the staff in other rooms, depending on the situation.

The staff will prioritise certain tasks or patients and work out an order in which things need to occur and which has the highest priority or requires to be carried out before others.

'If it's something to do with their treatment which needs dealt with there and then I guess you have to kind of do it, but if it's something that can wait till everybody is on, so you can go back and have a proper chat' (Dani, Registered Nurse)

'We don't spend a lot of time, sometimes we do, but not always, because there's not really time for, I spend my five minutes to ask them questions to fill in care plans, if any patients had a real concern, like the new patients who has just started dialysis, who has family problems and want to talk to us, obviously, people available to speak to them, when something happens in the room, the staff spend a lot of time with other patients' (Julie, Registered Nurse)

The nursing staff, particularly the registered nurses, identified that they would spend time with patients when there were fewer priorities, usually when everyone was on the machine and treatment had commenced for all patients.

'Maybe after the patient is on the machine, we sit and talk to them about their daily needs' (Julie, Registered Nurse)

Having other staff in the room and on shift can facilitate jobs to be done and work to be prioritised for the times when staff are available. Also, the non-critical or non-urgent jobs like organising folders or making up 'monthly bloods'⁶ can be undertaken.

'We've got other things to do like monthly bloods, but if there is a quiet time we can do things like that then, paperwork, update the bloods, no point in me doing it if other things to do, or there isn't staff around' (Dani, Registered Nurse)

⁶ Monthly bloods refer to the blood samples taken routinely every month to check specific blood tests. These are made up in advance of the day and are in the patients' folders ready for use when needed.

The time of day impacts on the time for patient care in the haemodialysis unit.

'We get a lot of contact though ... it all depends on the part of the day' (Edward, Patient)

Patients do not feel that dialysis or the treatment is the sole focus, they are prioritised and cared for during their time in the unit.

'It's not a case of them just putting me on, and then they are away again, I mean they don't do that' (Barbara, Patient)

Staff highlighted that patients find time with them important when they are on dialysis.

'I think they actually appreciate the fact that you've stopped and maybe if you do sit down to me I'd much rather be on (there) as opposed to standing over them, apart from that it looks like you're prepared to stay if you pull up a chair and sit down' (Lee, Registered Nurse)

5.5.5 Encounters between staff and patients

These were different ways in which staff or patients would initiate an encounter or engagement, or withdraw and disregard the presented opportunity for an encounter or engagement.

Many encounters were witnessed during fieldwork between staff and patients, highlighting different topics of conversation and different ways in which time was spent together during treatment. Different examples illustrate the various different ways in which encounters happened in the haemodialysis unit.

Robert was asked about her recent baby scans and how her pregnancy is going by a patient, this particular patient is nearby and not the one she is dealing with clinically at this particular moment

Bobby is asking the staff nurse about holiday plans, and she asks him about college course and his course work

When patients were receiving treatment, it was observed when patients and staff would take advantage of the situation, by being near a patient or during a more

clinical task.

22:55 twilight shift

There are 3 patients in the room and one nurse (the other is on her break). The nurse is sitting at the desk, looking round room.

Andrew (patient in space 3) takes his earphones out (he is listening to music on his laptop). 'Come here' he shouts over to the nurse and she gets up and goes towards him.

Whilst patients were on dialysis, or receiving treatment, most kept themselves busy or entertained or distracted with books or the television. However, when staff approached them to do a clinical routine procedure or task, they would sometimes give the staff their attention, and look for interaction from them when they were at their side.

Observation 3

Staff is at the patient's side, doing a check, staff member (registered nurse) has the folder in their hand and appears to be checking the prescription and the machine are the same-standard procedure in the checking process.

The patient has been sitting in the dialysis chair, with their headphones on and reading their book. As the nurse is doing this, the patient takes off their headphones and puts the book on the table in front of them.

The patient here stops reading to then speak to the staff who has approached them.

The following fieldnotes made during observation 11 demonstrates a situation where the patient waits for a staff member to be near her to ask for pain relief, despite staff being in the room although they are present in the room and using the computer.

Observation 11

Patient appears to be quite uncomfortable in the chair, she is moving and wriggling about, repositioning herself and the chair. She is swinging her legs over the side, and putting the back of the chair down and up, using the electric handset of the chair to help her positioning. She does this silently, she looks up towards the desk but the staff does not notice, she is on the computer and facing away from the patient, the patient continues to manoeuvre herself around on the chair. One of the support workers walks past – on their way through the room, to leave the unit- and the patients says to her as she walks past her chair ‘A, can I get some pain relief’

Figure 34 and the following fieldnote show the staff and patient both waiting for the machine, when nothing is said between them but the nurse is close by.



Figure 34: Registered Nurse standing and waiting

Observation 2 (Figure 34)

The nurse is standing beside the machine, and appears to be waiting for the machine to complete the haemodialysis. The patient is sitting up in the chair also waiting for the machine to finish. Nothing is said between the two, they just wait for the machine to signal the commencement of the next stage, coming off dialysis. The two begin to chat once the machine alarms, but there is 2 minutes or so of silence between them while they wait.

Patients identified that they can ask staff questions about their treatment when they are receiving their dialysis.

'I'll say ask the staff, the staff are quite willing, if you don't ask they will think you understand everything, but if you don't ask, then you know because that's how you learn' (Rita, Patient)

One patient felt that at times it was difficult to get the attention of staff when they needed something.

'It's difficult to get someone's attention sometimes, especially when it's a big room, and the staff are busy' (Donald, Patient)

5.5.6 Predictable Routines

'The patients know the routine, they know when they come in if it's been a good day or a bad day, if you're busy or what, you can tell by the atmosphere, if we are harassed!' (Dani, Registered Nurse)

There is a predictable pattern or routine of the caring procedures or practices that occur.

Samantha, the nurse, walks over to Eddie, the patient. She picks up his folder and looks at the machine. His folder already had his weight written down, she calculates his fluid goal but just responds to him with the final answer 'Taking 2.7 (litres) off today- that ok? Let's do your blood pressure' and walks away to the other side of the room to get the blood pressure machine.

From this fieldnote, the importance of the clinical tasks can be seen through the prioritisation of the programming the machine/UF calculations and blood pressure

over the welcome/chat/pleasantries which do not happen in the initial minutes of interactions.

'there is a fairly clear routine, getting people in, getting them on the needles, erm, and em, you know, checking their BP and all that sort of stuff and then everyone has a sit down just like the patients, do their paperwork and that sort of stuff, and then it becomes time for people to come off, and eh, go through the reverse routine, and then it all starts again' (Jerry, Patient)

Patient arrives and no one speaks to him, he doesn't speak to anyone in the room either. He puts his bag on his dialysis chair and then leaves the room again, probably to get his weight or to go to the toilet, he returns a few minutes later and then begins to empty the contents of his bag out onto the table, his laptop, DVD's, his phone, a packet of crisps. He then puts his bag on the small chair beside the dialysis chair and gets onto the dialysis chair, and arranges his pillows, getting comfortable and everything set up for his time during treatment.

This illustrated that whilst staff may want to support and allow patients' needs and requirements for dialysis, the practical issues and priority of getting on quickest from patients does not always allow for individual care.

'They always make it aware that they are at you, and what they are doing, and if they are giving you any medication, they always tap you, and say, they don't just give you it, they always tap you and say this is what we are doing now' (Emma, Patient)

'The lesser part is the physical part, because I think it's fairly routine, it becomes very routine' (Darcy, Registered Nurse)

Two excerpts below from fieldnotes show the knowledge of the procedures and the pattern of events which normally occurs, and the patients know what to do without being asked.

round my wrist' he says, she hasn't even asked a question on where to put the piece of tape she is still taping the loops of the needles, he knows what's coming...

The patient has been connected up, 2 needles in his fistula, the chair was raised for the needle insertion. The nurse is looking at the machine and increasing the pump speed, and the patient lowers the chair before the nurse has turned back to finish the taping

These examples demonstrate the predictability of the process, procedure or care. The patient knows will be asked to lower the chair once they are on dialysis so has already done this before the procedure is even finished.



Figure 35: Taping the needles

‘Matthew has his fistula arm out on the pillow, he is getting comfortable. Stella, the staff nurse is at the end of the patient chair focused on the trolley and getting the equipment ready. He doesn't even ask the patient to put their arm out- it automatically migrates to the pillow the patient has put there as part of the ‘going on’ process’

As the care is similar every time, and the patients understand what is happening, the discussion between the staff and patients can be very minimal.

These questions were posed from staff when putting a patient on dialysis regularly during observations.

‘shallow or deep’

‘what angle’

‘12 o’clock and shallow?’

‘and what’s the angle?’

‘We reverse your lines?’

Some of these expressions relate to the angle that a needle requires to be inserted into the fistula, but without being involved in this area these expressions would require more explanation as to what the question is asking, but the patients know that they are referring to the needle insertion. It is a common question for the staff to ask the patient.



Figure 36: Preparing equipment and the fistula for cannulation

Routine Questions

‘Things you notice that, because you have been dialysing long term, and they will explain that to you, that’s part of the treatment’ (Emma, Patient)

The questions asked by both registered nurses and support workers are known by the patients who attend the unit. These questions regarding how they are, diet and weight or wounds are asked to patients regularly when they attend the unit. They are not always asked at the same time, some staff ask these questions when they are in the commencement phase of the dialysis, others ask during the lull or middle period when treatment is occurring, and some ask when the patients are in the final stage of dialysis and coming off the machine.

Routine procedures

‘The procedures are reassuring to me’ (Jerry, Patient)

There are elements to dialysis care and practice in the unit which the patients know will happen, and in a particular order.

‘They go through the same procedures’ (Martha, Patient)

‘Think in general mostly the nurses do that, cause obviously they get taught a routine, as well of how it works, so they are carrying out that routine, well you are hoping they are going to carry out that routine that they are shown what to do yeah’ (Emma, Patient)

‘Once they are all on and they are all established on their dialysis, we would go round and do the drug round which is the epo’s, and our IV⁷ iron and getting any drugs that they need, that they want, maybe quinine or whatever to make their dialysis more comfortable, (Charlene, Registered Nurse)

‘Can you give me your date of birth, or check my date of birth, I’m like, I’ve been here a year, do think do you not remember it by now! (giggles) but I understand the procedures, it covers them’ (Martha, Patient)

One routine procedure which staff do is to get all the dialysis spaces ready for the patients before they arrive. This includes the machines being lined and ready for the

⁷ IV is intravenous, Intravenous iron is a medication given regularly for renal patients. It is given when on dialysis into the machine during treatment.

patients and their folders being on the correct space. This is a process practiced by both the registered nursing staff and clinical support workers. Some staff write the names and dates onto the paperwork before they arrive, and even get the tapes and needles onto the table or trolley ready for use (Figure 37).



Figure 37: Registered Nurse preparing the dialysis space

‘All set up and that’s them ready for their session’ (Charlene, Registered Nurse)

Sometimes the care is so predictable that it isn’t a positive experience.

‘There are certain ones who make it impersonal’ (Betty, Patient)

Routine of care to help patients cope

The routine care and procedures allow patients to build a routine around what they know will happen. This predictability and routine allows the patients to have an element of control.

The routine for patients allows them to have a pattern or routine, which they could use as a coping strategy.

‘You just get yourself into a pattern, a routine, that’s the only way your brain copes with the pattern, is to get into a routine, to focus on things, establish a routine as well you do things in a certain order, so that’s been a coping strategy throughout my life’ (Jerry, Patient)

‘My routine as I say, when I go on the machine I read, get my breakfast, then usually after that I have a sleep, I wouldn’t say my routine has changed that much’ (Emma, Patient)

A predictable aspect of the dialysis routine was the trolley with tea and either toast or sandwiches depending on the shift and time of day.

If this did not appear at the normal or usual time, patients would alert staff to its non-appearance and enquired after the tea.



Figure 38: The tea trolley with sandwiches

Routine of care to help with boredom

Patients felt they needed to make the dialysis treatment and surrounding experience part of their normal routine to help get through the treatment and make it more bearable.

‘(Dialysis) just trying to treat it as a normal part of my routine, because it has to become part of my routine, there is no point thinking it’s not going to happen tomorrow, or the next day, you know, the realisation is that for the foreseeable future, I’m going to have to do this dialysis, and keep my quality of life, and it’s obviously changed with other things, setting up as a routine, has helped ease the boredom and establish the routine’ (Jerry, Patient)

A patient has to have a few different things to help keep them busy so the time in the unit and the treatment is more tolerable.

'Some mornings because I'm more tired than others, I don't read as much, I like to try and read a wee bit to keep my mind occupied'
(Emma, Patient)

Patients would bring in a variety of different activities so depending on how they felt, they would have things to do during their treatment.

Some patients used the patient televisions regularly, but if these did not work or had a problem, some patients would have nothing to do.

Staff try to keep the conversations different so they rhythm and routine differs and does not get stale.

'I try not to keep the conversation confined to set questions, cause first of all that's boring and patients I would imagine would get bored of it cause they would see it as 'oh he's asking me the same rubbish and isn't really interested in whether or not I actually did something at the weekend' (Jo, Support Worker)

Staff Routines

Staff make a list with the times, discuss breaks around the times of the busy periods and focus on when patients are going to be coming off the machine. This happened in every shift or patient group, but in different ways.

'I would probably still ask what's been going on, it's just general, it's like being at the hairdressers, always ask where you going on your holidays and we always ask, start of conversation, with 'how have you been since you were last in', and I guess it's just habit now, and I probably do it to everybody, and some of them say I've been fine and some of them it will start a whole conversation before you know it you have been there 20 minutes, (Dani, Registered Nurse)

Some staff would have a discussion, whereas sometimes one staff member would have organised or planned the next group without discussing it.

The staff acknowledge the specific routines they have within the unit, and their own personal routines. This is in relation to how they organise their own workload and prioritise different activities, as well as the wider unit routines which everyone follows.

The tea trolley is usually at specific times throughout the day (8.30am, 11.30am, 3pm, 8.30pm) and both staff and patients are aware of this routine and notice when it is late. Cleaning is usually an activity carried out in the evening or at the end of the shift.

5.5.7 Speed of Haemodialysis

As previously shown, clocks and time (see section 5.2.7) are important objects in the haemodialysis environment, there is also a focus on speed within the area and getting on and off the machine as quickly as possible, by both patients and staff.

'The star of the show is Frank (one of the registered nurses). He just goes wap, wap. And that's it' (Betty, Patient)

This quote relates to the speed of the needles being inserted, and getting on to haemodialysis

'Putting their needles in, without blowing the fistula, if they get put on the machine quick without any complications' (Jan, Registered Nurse)

The staff know speed is important, and they know the patients' priority is to get the on the machine as quickly as possible without problems or complications.

'You just got to get on, and be away sort of style' (Bob, Patient)

It is not just getting on the machine quickly, it also includes having no complications which would therefore require patients to stay in the unit for longer than necessary,

'I want to go on as quickly as possible, get the dialysis done, and get out' (Martha, Patient)

Considering the way in which the patients are allocated, staff to put them onto dialysis can cause some frustration.

'And we are waiting outside when they could be putting someone on, just that wait, to be it would be beneficial cause I would get home, get out the door quicker' (Barbara, Patient)

Barbara is suggesting here that staff are available in other rooms to put her on dialysis and views beginning the dialysis treatment as quickly as possible to be a priority for her.

When patients started, and were new to dialysis, they did not understand the processes and why things would not always be ready for their arrival.

'I couldn't understand why the machine's not ready, why is it not ready, but then I realised, there was maybe someone on the bed 5 minutes before I came in, so it needs to go through all the procedures to clean it up' (Martha, Patient)

Some patients find that their dialysis experience is easier when it feels quicker and does not drag.

'If it feels like it went quicker, then I feel better, but if it drags then nuh, you're looking at the clock every 2 minutes, if the shift feels it went quick, then I feel better, that's me I can get home now' (Judy, Patient)

Staff also understand that patients want to get onto the machine quickly as it has an impact on the patients.

'I think it's important you don't delay it, it's a long day, a long session for the patient' (Pat, Registered Nurse)

Staff also have a focus on the speed of getting patients in to the unit and on the machine, and also off the machine in a timely manner, so there is little effect on the next patient group and shift.

'Getting them on and getting them off as quickly as they can and make my day run smoothly' (Holly, Registered Nurse)

The staff identify that they do a lot during their shift with patient numbers and treatment times.

'We cram a lot into the day' (Charlene, Registered Nurse)

During the fieldwork, the speed at which staff would get patients on the machine, and therefore the early finish of treatments for patients was something of which staff would be proud.

‘Our times are good’

*** something which is said frequently between staff in the room,
and to other rooms when looking at the patient list*

Despite speed of commencement of treatment being important, it could not always be the priority.

*A patient arrived for treatment and asks loudly to the whole
room where they are to sit for dialysis, ‘where am I?’*

*The support worker points to the empty chair in the room ‘but
you know I hate this space’ says the patient, ‘well that’s the
space which is ready the quickest’*

Patients really valued getting on the machine as quick as possible, and would sometimes sit in the space they didn't like or in the chair that wasn't as comfortable in order to get on to the machine quicker.

5.6 Summary of Context Chapter

This chapter presents the detailed descriptions and data collected in this ethnographic study to illustrate the haemodialysis unit, the people who can be found in this particular area and the rhythm to the dialysis shift and the care provided.

It is intended to provide a backdrop to the main findings chapter and to show the researcher was really there, in the field.

This chapter considered findings related to the environment, with the layout and make-up of the rooms and the shift patterns of patients and staff. Particular aspects of the environment featured throughout the research. The importance of the keys and the board to identify who was in charge, as well as various different aspects provides an in-depth understanding to both staff groups and haemodialysis patients.

The rhythm of haemodialysis suggested that there was a shared understanding of the routine or pattern of caring activities which occurred in the haemodialysis unit.

The rhythm of haemodialysis describes the pattern and predictability to the way in which haemodialysis care is carried out in the unit, with particular elements to this rhythm impacting and relating to the delivery of patient care. The lull during the shift was an important period where sometimes very little interaction would occur between the patients and staff, whereas the beginning and end of dialysis treatments was a much busier time and interaction and engagement with patients and staff was necessary to carry out these particular aspects of treatment and care.

Chapter 6 Findings: Direct Patient Care

6.1 Introduction

This chapter will present the findings of the study, to illustrate the themes identified exploring the research aim from 8 months ‘in the field’. The aim of the research was to gain an understanding of patients’ and staff perceptions and experiences of ‘direct patient care’ within the haemodialysis unit. By using thematic analysis as the form of data analysis for the data collected, themes were identified which explored this predetermined research aim and answered questions related to ‘direct patient care’.

6.1.1 Structure of this Chapter

The themes identified were classified into broad headings, and within them smaller sub-themes, in relation to direct patient care and the research questions:

- The experience of direct patient care:
 - *A combined process*
 - *Primarily focused on clinical tasks*
- The elements of what constituted direct patient care:
 - *Individual*
 - having different needs
 - feeling like an individual
 - individual care
 - *Comfortable*
 - physical comfort
 - inter-relational comfort
 - *Safe*
 - staff positions
 - safe practices and procedures
- The Delivery of Direct Patient Care:
 - *Active Care*
 - Time together
 - Verbal dialogue
 - A necessity or requirement
 - *Passive Care*
 - Being physically visible
 - Sounds of passive care
 - Being physically available
 - *Doing Both: Active and Passive care*
- Connections in the Haemodialysis Unit:
 - *Individual Connections*
 - *Group relationships*
 - *Boundaries*
 - *Maintaining a connection*

These themes are now described in detail, using data collected from the research. Similar to the previous chapter, the results will be presented dependent on the participant or the method of data collection (see Figure 3 and 4, in Chapter 1.5 structure of thesis) and are presented for the findings to be viewed as trustworthy by others.

6.2 The Experience of Direct Patient Care

This section relates to the ways in which the respondents considered and described what direct patient care was within the interviews from all the different participant groups. It will describe the findings related to both staff and patients' perceptions and experiences of what 'direct patient care' is.

Some photographs and fieldnotes from the observations also highlight situations of this participant-defined 'direct patient care'. There was a difference between the way patient and staff groups understood what direct patient care was. Patients focused on the entire experience, not just the dialysis process, as direct patient care, whereas in contrast the staff mainly have a task focused interpretation with, particular emphasis or focus on the haemodialysis related tasks.

6.2.1 A Combined Process

The idea of direct patient care being the whole process or everything came mainly from the patient participants.

Direct patient care was;

'Not just putting you on, have a good dialysis, thank you, see you next time' (Martha, Patient)

It was identified as the whole experience or process, more than purely the physical aspects of haemodialysis from the patient respondents.

'Direct care for me would be that they just take care of you, they come and have a wee word with you. Reassure you that everything is going to be alright, the machine, they give you information if you ask for it, your pump speed and things like that' (Betty, Patient)

This patient quote highlights the many aspects, all of which contribute to direct patient care; a mix of clinical and technical features as well as care, reassurance and a chat with the staff.

‘As far as I can see it’s there from start to tail’ (Jerry, Patient)



Figure 39: Patient and Nurse chatting together

Figure 39 shows the nurse and the patient together. They are chatting while the nurse is about to begin the process of taking the patient off the machine at the end of their treatment.

Patients regarded direct patient care as encompassing all aspects of the things they require from start to finish or their arrival to their leaving and everything in between.

Direct patient care was also identified by the patients as something which exists as part of their treatment and happens as part of their attendance in the unit and the care they know they will receive.

‘They could leave me in the reception for 10 hours! So yeah, the fact that they are not disappearing my name off the list, but so, that is all care’ (Jerry, Patient)

By remembering the patients are there, bringing them through to start their dialysis and making sure they have a space for them to have their treatment also allowed the patients to feel they are being directly cared for by the staff.

Care was also identified to be associated with the staff who are working and who puts the patient on dialysis.

‘Care differs ... aye, definitely. It depends on who puts you on’ (Betty, Patient)

6.2.2 Primarily focused on clinical tasks

In contrast to direct patient care being regarded as the whole process, the majority of both registered nurses and healthcare support workers described direct patient care, within a haemodialysis context, as having the main focus on different and specific haemodialysis tasks or duties they carried out during a shift with patients.

Registered nurses commented on fistula cannulation, drug administration, machine programming as particular examples of direct patient care. These were all described as part of the ‘usual’ direct care for haemodialysis patients.

‘Direct patient care involves the usual things- you have to put people on dialysis, you have to do it safely, you have to take them off dialysis, these tasks are non-negotiable, and dialysis is very task orientated’ (Charlie, Registered Nurse)

This quote highlights the specific haemodialysis related examples of direct patient care from one registered nurse. An example of a ‘non-negotiable’ task or part of dialysis direct patient care is the taking of blood pressure, something which is part of the dialysis putting on and taking off procedures, and the giving of medication whilst on dialysis.

This task orientated idea was prioritised by the staff in their interviews. The focus on these specific tasks by both groups of staff indicates how important these tasks are and how highly they are valued by the staff. These tasks were specifically dialysis-related, which included the physical processes and the non-negotiable parts of dialysis treatment. There was a particular focus on the more medical issues from staff, relating to assessment and also education on kidney disease and dialysis, as well as associated things like their ‘perm-cath’⁸.

⁸ A ‘perm-cath’ or permanent catheter is the local name given to the tunnelled central line used for haemodialysis treatment

'Taking vital signs on arrival, assessing the patient, their condition, how do they feel? Assessing what fluid to remove, educating about their disease, start of dialysis, making sure their medication, what they are prescribed from the doctor, educating them on the side effects of dialysis, maybe they have a perm-cath, care of the perm-cath, care of the fistula, ...and basic care if they need any' (Julie, Registered Nurse)

This quote highlights the wide variety of dialysis related tasks which staff regard as direct patient care, but along with the inclusion of basic care if it is required, indicates that some patients are different than others, or have different needs to be met, which is different to their dialysis tasks which is the main focus.



Figure 40: Nurse checking blood pressure and providing reassurance to a patient

Registered nurses in the interviews described direct patient care as if it was almost split into two different aspects or parts of care.

One nurse commented on her role having two aspects, one being the dialysis side of things, with a focus on the medical treatment and then the other side of things, which has a focus on education and their wider medical issues, for example, their diabetes or their diet.

'Ultimately they are down here (in the outpatient haemodialysis unit) to like, take toxins out of their blood and any excess fluid, ultimately that's more like the medical treatment, and okay we have a part to play in that, we have other roles, and a lot of that I would put down to

education and educating them via their diet, taking care of their skin, being aware if they are diabetic or not, ensuring they know what a diabetic diet is, what good control is, ' (Tina, Registered Nurse)

Another nurse also acknowledged the two split sides to the direct patient care, but that the haemodialysis was a greater, more important part of this care.

'You are doing other things for them as well, toileting, doing dressings, whatever, and that's a much smaller part of our workload than just the dialysis' (Marty, Registered Nurse).

The support workers also described how they provided direct patient care, and when they did so, it was similar to the registered nurses, as it had a more task oriented approach or focus.

'I'll take them in, they get their blood pressure done, maybe ask them a couple of questions, how are you feeling today, anything you want to talk to me about, anything like that have a bit of banter with them, you know, so patient care is just erm, making sure they are alright, get them on their treatment' (Billie, Support Worker)



Figure 41: A nurse giving medication whilst patient is on haemodialysis

This quote indicates the variety of different tasks which the healthcare support workers acknowledge as direct patient care, in the clinical tasks of taking their blood pressure and getting them onto treatment, but also highlights that asking how patients are and talking to them is something they view as direct patient care in the haemodialysis unit.

The registered nursing staff did describe contact or spending time asking how patients were feeling as a way of providing direct care, but this was usually secondary to clinical skills or tasks.

'I think it is complex, and being understanding, being caring about them, plus the clinical side of it' (Julie, Registered Nurse)

One nurse even acknowledged spending time with patients and supporting them psychologically was more important than the more clinical or dialysis process focused DPC.

'I think the compassionate side of it and the psychological side is probably greater than the physical' (Darcy, Registered Nurse)

Direct patient care for one nurse did include being with the patient and talking with them, with another nurse acknowledging it was not just putting them on and off the machine, highlighting the difference in the various tasks and ways in which direct patient care is performed.

'Direct patient care, it's not just putting them on the machine and taking them off' (Charlie, Registered Nurse)

This indicates the task focused approach and the understanding of the necessary, unavoidable direct patient care, but that care is more than just this one dialysis related task. Direct patient care is providing the things that patients want and need, especially related to their illness and treatment. Direct patient care is provided in different ways through these different tasks and activities, but staff view it as something they should be doing and that is has an importance, although secondary to dialysis tasks, in the dialysis area.

One registered nurse explained during an observation session about moving back to this unit, having had some time away in another area. She was an experienced dialysis nurse but acknowledged that as she did not yet know the patients, things were different.

Observation 1

***‘Because you don't know the patients as well – my speed....
having to do a full assessment, look at them and their fistula,
there is no time to get to know them (the patient), next time I'll
be a bit quicker so we'll be able to talk then’***

*****Rachel (Registered Nurse) as part of an informal
conversation during observation session***

These non-haemodialysis tasks were identified by staff, but they identified the lesser priority that they had. One nurse felt this contrast and was aware that staff purely focus on the dialysis at times, and not the whole process/experience....

*‘they (the patients) are still getting the dialysis care they came for,
but they are not getting the full package, in terms of holistic, we focus
on the dialysis and the machine and we forget about the person
sitting in the chair’ (Jan, Registered Nurse)*

When describing direct patient care, one of the nurses acknowledged that it was

*‘More than just the dialysis’ ‘a smaller part of our workload’
(Marty, Registered Nurse).*

These two comments highlight the awareness of other aspects of care, rather than just the dialysis related tasks or jobs, but the haemodialysis treatment and care which relates to this treatment remains the main focus.

Another registered nurse did acknowledge there were other aspects to direct patient care, similar to the patient understanding, but still with a clinical and task focus.

*‘But direct patient care ... it's your stocking up, making sure your
area is clean and tidy, it's just about everything, it's about us all
mucking in together’ (Charlene, Registered Nurse)*

This also suggests there is an awareness of the other activities which are direct patient care, but not the primary focus.

*‘But then there's other aspects of direct care, just even, even just
having a chat’ (Holly, Registered Nurse)*

There was a focus or emphasis on the physical tasks and processes of dialysing as direct patient care.

'I'm just going to put on Matthew, then I'll come back to you'

This quote from a nurse during an observation indicates the priority to the dialysis related task of 'going on the machine' than the patient's request. This also illustrates the focus on time and speed from both staff and patients, highlighted in the previous findings chapter.

6.2.3 Summary - Experience of Direct Patient Care

Direct patient care means different things for both the staff and patient groups, and both groups emphasised different aspects of direct patient care in their responses. The patients viewed direct patient care as the whole dialysis process and time in the area, encompassing the entire dialysis process, the experience of everything and feeling cared. In contrast, the nursing staff, both the registered nurses and healthcare support workers, viewed direct patient care with a huge focus on dialysis related tasks. They were more focused on the ideas of carrying out tasks or delivering more physical dialysis care. These more clinical skills or tasks were prioritised by staff when listing different aspects of direct patient care, and psychological and more emotional care was considered secondary to these dialysis tasks.

6.3 Elements of Direct Patient Care in Haemodialysis

Despite direct patient care being explained in different ways by the groups of participants, the data suggested that direct patient care in this area still aimed to provide three distinct things as part of the care- safe, comfortable and individualised care. These three elements were key parts of DPC and each of these will be explored in turn in this section, with data from the interviews, fieldnotes and photographs to illustrate these themes and the sub-themes.

6.3.1 Individualised care

Within the haemodialysis environment or clinical setting, there was an acknowledgement from both the staff and patient respondents that care is different

for all patients. Care in the dialysis unit can be unique to the patient and is dependent on their needs.

An aspect of individual care is actually predictable care or routine, which is also a part of the dialysis care due to the repetitive nature of the treatment and particular processes and individual care is a way of trying to make the process less repetitive, predictable or mundane. This is covered in the previous chapter, as part of the context of haemodialysis.

There are three subthemes within individualised care which will be explored in turn.

Having different needs

The staff in the haemodialysis unit identified that the patients who attended the unit are all different, and therefore have different requirements for the care provided to them by the staff. Charlene directly identified in her interview that patients are different from each other.

‘Not every patient is the same’ (Charlene, Registered Nurse)

Another example from a registered nurse suggested that care was about focusing on the needs of the patients.

‘What is care? Well it seems like a trick question...it’s really just taking care of any needs that they have’ (Marty, Registered Nurse)

The suggestion that ‘what is care?’ was a trick question, proposes that she views care as an obvious or basic part of nursing or haemodialysis treatment.

Marty continues on to differentiate between the usual regular out-patients and ward in-patients who visit the department for their dialysis treatment. She felt that there was a difference in their needs or care requirement which related to the patient’s status as either in-patient or out-patient.

‘The ward patients probably have a little bit more input, but you may find that that’s more physical and you are doing other things for them as well, toileting, doing dressings’ (Marty, Registered Nurse)

The registered nursing staff identified that they provide care through the provision of haemodialysis and by doing other things depending on the patient’s needs. The care

or needs that patients have can be different due to length of time on dialysis, as the newer patients may require more support around the treatment, and then as they become more knowledgeable they need less from staff and other issues become more important.

‘Some of the new starts sometimes, need a bit more support, we all know it’s hard coming in three times a week, it totally turns your life upside down (Dani, Registered Nurse)

The quote illustrates the difference in needs and suggests the new patients who have just begun dialysis have a lack of understanding which is focused on by staff, and then as they learn more about treatment then focus on other issues.

*‘As time goes on, their dialysis becomes less important, and other issues surrounding it like the transport and all that kind of stuff’
(Marty, Registered Nurse)*

Marty gives examples like the temperature of the room, being on the correct chair or space in the room, or the machine being on a specific side, which become more important to more established patients and are aspects which can be individualised for the patients.

Staff in the haemodialysis unit viewed patients as having different needs or priorities of their care as they become more established on haemodialysis.

Feeling like an Individual

This sub-theme focused on patients feeling like they were not treated the same as the other patients, that patients get care which is tailored to them and their needs.

*‘They treat you like an individual, not like you are a cattle of meat, just coming round in, just fling you in and fling you out after it, that’s what I like about it, you know, it’s like a wee family unit really when you think about it, you get that feeling everything is alright’
(Judy, Patient)*

Here Judy highlighted that she wanted to feel individual and have an individual experience. She felt the staff were able to do this for her when she attends for her treatment.

Staff also identified that patients should feel individual and not treated the same, they need to be treated or cared for in a way specific to them.

'Each person is different, so it's almost like you have to approach everyone differently, it's, I can't just treat everyone like Paula, who will have a conversation with someone across the room, with several at the same time, cause' she is so sociable, and that's a completely different conversation than having one with someone like Viv, or Brooke' (Tina, Registered Nurse)

Staff in the haemodialysis unit, both the registered nurses and support workers, strive to treat the patients as individuals and the patients know that they are treated like people and not numbers.

'My main goal is not to treat them like a patient... it's not always about being a patient, it's about being a person' (Lewis, Support Worker)

'The care that you're giving the patient is individual for them, and not for anyone else' (Angie, Registered Nurse)

The patients want to feel like a person, and because of this they can then speak to them about their care or treatment or condition.

'Makes a big difference you are not a number, you know you're a person, you can have these discussions with them you know, which makes a big difference' (Martha, Patient)

Patients want to feel individual, and the staff try to make the patients feel this way.

Despite the understood importance of treating patients as individuals, there was also a concern that some staff did not always do this, and would focus on the machine and treatment and not the patient.

'We focus on the dialysis and the machine, and forget about the person sitting in the chair' (Jan, Registered Nurse)

Providing Individualised Care

The third sub-theme which makes up the theme of individualised care is how this individual care was provided in the haemodialysis unit.

Individualised care was provided by the staff, both the registered nurses and clinical support workers, using different forms and the staff know that a one size fits all approach is not necessarily going to suit all patients.

‘Professional, caring, cause the whole thing with nursing is to care, and that can take loads of forms- doesn't mean hugging someone- you can be quite firm but caring as well, it doesn't have to be all lovely and patting on the head, it can take loads of forms but still be really good care’ (Charlie, Registered Nurse)

‘You can't deal with a patient without speaking to them, you can't have a patient come into this unit and not open your mouth to them, you have to ask them something’ (Lewis, Support Worker)

‘They always ask how you are, how your diet is, how are you feeling today, if you have any open wounds, if anything is worrying you... they ask questions daily’ (Emma, Patient).

These three quotes from the different participant groups illustrate the variety of ways in which individual direct patient care is provided to patients. This idea of staff asking how patients are, and being unable to care without speaking to them highlights the importance put on the verbal communication between staff and patients. Verbal communication will be covered as part of the active care theme in this chapter.



Figure 42: Patient getting onto the dialysis chair

Individual requests from patients are acknowledged and acted upon, like chair, dialysis space or positioning the machine and screen in the patient's preferred location.

Cyril is on dialysis now, the nurse is clearing up the area and puts the folder on top of the machine. 'Can you turn the screen, I can't see it' he says to her as she is putting down his folder.

Patients choose the way in which they want some aspects of their care or direct patient care to be whilst in dialysis.

'They maybe miss out on some conversations but again it's choice, some are much more talkative than others, some may fall asleep as to avoid the conversations, keep themselves to themselves (Tina, Registered Nurse)'

Some choose to sleep and therefore have little contact with the staff during their treatment, others will converse during their dialysis with all the different staff in the unit.

One nurse acknowledges trying to ensure the individualised care, despite the routine of the dialysis procedures and the importance to the patients to not feel routine.

'It is a routine thing, it has to be sadly, for the maintenance treatment of their kidney failure They (the patients) don't want to feel routine, they don't want to feel like another one, they want to feel like an individual, and they and we as part of that care, have to make them feel as if we care about them, and show that, demonstrate that' (Darcy, Registered Nurse)

Routine is one way in which patients can establish their own care pattern and use it to cope with treatment. This is particular finding is further explored in the previous findings chapter.



Figure 43: Registered Nurse spending time with a patient during treatment

Summary

Individualised care was highlighted in the research as three themes. Patients and staff acknowledged that all patients have different needs, and this was something that needed to be addressed by staff when patients were in the unit. There was also the importance of patients feeling like an individual and the different ways in which individual care can be and was provided in the dialysis unit.

6.3.2 Being Comfortable

The theme of being comfortable when on dialysis was a recurring concept from both the patient and the staff groups.

Here Betty highlights the comfort of the dialysis unit as a whole;

'I like the comfort of this place. I don't fancy going anywhere else'
(Betty, Patient).

Comfort was an idea which was expressed from the data and is now classified as two types of comfort: physical comfort and inter-relational comfort.

Physical comfort

The three groups of respondents all identified that making patients physically comfortable was an important aspect of the dialysis care.

One of the registered nurses noted that one of their aims was to

'Just get them (patients) comfortable' (Angie, Registered Nurse),

which was done by either communication, or getting patients drinks or their medication, or

'If they like a big blue chair, you give them a big blue chair' (Angie, Registered Nurse)

The use of pillows to make patients comfortable was something observed, particularly in the set-up of a patient and was carried out by all three groups, either by patients asking for pillows or the staff offering them or just bringing them over without asking.

There are two pillows on each dialysis chair, this is the normal practice although some get more or need less, the patient has put one of them on the plastic chair beside them whilst they get onto the dialysis chair and position themselves using the handset to raise the legs or back of the chair. Lewis, the support worker has come over and asks how they are, and puts on the blood pressure cuff. They come round to the other side of the chair, pick up the pillow and the patient raises their arm (the fistula arm) and the pillow is put down by the staff underneath the arm, for their comfort during dialysis'

This fieldnote shows the knowledge the staff have on the patient's physical needs for comfort, by knowing where they would like the pillows without asking the patients. This illustrates the way in which staff can provide the physical comfort and individualised care without asking the patient what they want as they already know.

During the fieldwork and observations, at the beginning, prior to patients arriving in the unit, staff would sometimes put out the extra pillows which patients would request before arrival, as the staff knew who would want extra pillows or the inflatable mattresses to go on the chairs.



Figure 44: Patient in the 'big blue chair' for comfort

The staff ensure physical comfort for patients through individualised care, with the position of the pillows allowing the patient to be more comfortable during their treatment.

'They move all the bed. Move the machine. If I don't like the bed then they'll move the bed, give me this one, if I want cushions, they'll give me that. They can't always provide blankets and that during the day, cause' I find the morning and afternoon patients will be using blankets, and I think it can get a bit chilly at times, and I just find that when I am on dialysis, the top part of me is cold, not the bottom part, but the top part so you are always, trying to get me warm' (Martha, Patient)

The provision of physical comfort is something both staff groups do, with a support worker stating specifically that making patients comfortable is something which is part their role.

'The person who gets them (the patients) the food, gets them the ice, who gets them a blanket and makes them comfortable' (Jo, Support Worker).

One patient described the support worker group as

'They know what you want, and they know what you like, and they do it for you' (Sandra, Patient)

An example of the staff providing physical comfort is through the provision of cups of ice already being on their table when they arrive for their dialysis.

The healthcare support worker staff group are particularly focused on the comfort of the patients, as they are able to assist in this aspect of their care. The healthcare support workers do get to know the patients and therefore can know how to help in their comfort from previous encounters.

The staff know the patients and their routine or requests, due to the regularity of their attendance in the unit.

'I know what these patients need on dialysis in terms of, I know they always have quinine, I know they always want a blanket, and I know this because of experience, cause' I have cared for them over a long period of time' (Jan, Registered Nurse)

Patients' preferences, like how many pillows or if they like the mattress or blue chair are not normally part of the care plans, and are just things that are 'known' in the area, or one staff will know and instruct the other staff to do so.

Inter-relational comfort

Comfort was also something which was felt through the people in the room.

When patients knew the staff and patients in the room with them they felt comfortable and settled.

'I felt I had a lot of comfort in that room, I had settled in it, I knew everybody and I knew everything that was going on with them' (Betty, Patient)

Within the registered nursing staff group, they felt comfort was something which they needed to try and provide in the care they provide to the patients, something that they as a group could do.

'I want to just make them feel comfortable' (Charlene, Staff Nurse).

This was achieved by the staff by providing a friendly environment, being approachable, or chatting to them about something they have in common.

'The more you know that you know that person, the more you know all your patients, it gives them that bit comfort' (Lewis, Support Worker)

Staff also understood that patients needed to be comfortable for their entire time in the unit, not just the beginning or the end when the staff are always with them providing more clinical care, staff acknowledge that it is the entire time they are there, making sure they are comfortable throughout their dialysis.

Patients also acknowledge that this is something that staff try and to achieve, and do achieve. One patient particularly described the staff meeting him with a 'friendly face' allowed him to be comfortable.

'That's what they are there for, they are there to reassure me, make sure I'm comfortable with it' (Betty, Patient)

The staff provide comfort in the way they are towards the patients, and their attitude which makes the patients feel more comfortable, even when they don't want to be in the dialysis unit.

'The staff make it easier for you to come in, cause' there is many a time I've said to my hubby I'm not coming back, I no doing this anymore, I cannae do this anymore, and he'll say 'well you know the alternative'' and the staff do make it a lot easier for you by the way their attitude and how they are with you, and that's really good' (Sandra, Patient)

Comfort was felt though the presence of the staff in the room, and sometimes some rooms were felt to be more comfortable than others.

'Always somebody there and they are beavering about ...but aye I felt better in room three, more comfort (Betty, Patient)

Betty, one of the patients, identifies here that the comfort is higher in a particular room due to the staff, their presence and working practices and looking busy made her feel more comfortable whilst she received dialysis.

There is no set way that the comfort is achieved ('people do it their own way'), patients mentioned the different ways that the staff make them comfortable, but they do make sure everyone is comfortable. Patients commented on staff being

approachable, understanding, making things pleasant through jokes and being nice, all of which contributed to them feeling comfortable.

'Letting them know that you are there if there is anything that they wanted, or wanted to speak about' (Dani, Registered Nurse)

One way of providing comfort is when patients feel cared for and that staff are looking forward with them, rather just considering the current situation.

'You are looking to their future as much as they are' (Darcy, Registered Nurse)

The staff knowing the patients was a key part of the patients feeling comfortable when coming for their dialysis treatment.

'When you come through the door, they know your name, they know who you are' (Emma, Patient)

One way which comfort was provided to patients by staff was through hand-holding and their presence.

She (the nurse) is smiling at her (the patient), and holding her hand, whilst the needles go in'

'Actually it's probably the comfort of, maybe the warmth of your hands, and just and having somebody there with you' (Holly, Registered Nurse)

Staff also comment that the caring activities they carry out for patients allow the patients to feel comfortable when coming for treatment.

Staff acknowledge the patients when they arrive, and even the ones passing through the unit are addressed and spoken to by the staff (and patients), who they see on their way to their dialysis chair.

Comfort and discomfort can be felt through the people in the room. One patient acknowledged that sometimes staff make it uncomfortable for them, due to their presence and the way they care for them.

'It's ma care, and I'll have what I want to a degree, and a happy medium, and that's the way it's gonna be, if I think I'm being treated off-ish them I'm going to say something ken. Cause it's uncomfortable' (Betty, Patient)

By this staff member caring for Betty in a way she didn't like, she found the dialysis experience uncomfortable, highlighting the importance of the way in which staff approach and care for the patients.

Staff describe the comfort provided due to the staff member as something which some are better at than others.

'There was someone else the other day and they are kind of drawing them out, I don't know who it was, I think some of them have it and some of them don't' (Marty, Registered Nurse)

It also depends on who patients feel more comfortable with, which may not be the most experienced or qualified member of staff.

'Who people feel comfortable with.....somebody who is a really good listener, I don't think it makes any difference about how experienced you are, I think some people are better at it than others, at listening, and experience doesn't have much to do with it' (Marty, Registered Nurse)

This quote indicates the potential differences in patients feeling cared for, depending on the particular staff member and how they care for patients. The staff who are identified by this nurse as 'good listeners' are able to make patients feel more comfortable than potentially the more senior or experienced ones.

Jerry here finds the comfort he gets from the staff by not being robotic, by being people allows him to be and feel cared for.

'It's good to see that most people are human and are not robotic clinical machines, cause you know, I'm sure they are not very good, it doesn't really help the process of care, if they are purely robotic' (Jerry, Patient)

Summary

Being comfortable is something that the patients want, and the staff and the environment can allow the patients to feel comfortable or uncomfortable through

their presence or the environmental factors, such as pillows and cushions, and the way in which staff provide care.

6.3.3 Safe

All three respondent groups identified the idea of being safe as an important part of haemodialysis care, with regards to both care provided by the staff and as part of patients being cared for.

Staff identified that making patients safe and supporting them if they are scared or frightened is an aspect of their haemodialysis care.

‘I have seen young ones and old, frightened, so hopefully part of my role is to allay their fears’ (Tina, Registered Nurse)

The theme of ‘Safe’ is made up of sub-themes; staff positions, and safe practices and procedures.

Staff Positions

One way in which patients feel safe or that staff are able to ensure the safety of patients is by watching the patients when they are on dialysis.

Being in sight of the nurses was a comment that patients made frequently, staff keeping an eye on them or being watched all made the patients feel safe and cared for.

Cause although they are sitting at the desk, they are constantly watching you, watching all the patients to make sure they’re ok’ (Sandra, Patient)



Figure 45: Registered nursing staff at the desk

Here, in Figure 45, the staff member is sitting at the desk watching the patients who are on dialysis, something the patients know occurs and expect.

The patients know the staff watch them and keep an eye on them, which makes them feel safe and secure while in the unit and when attached to the machine and receiving haemodialysis.

'They (the staff) kept an eye on me' (Rita, Patient)

This understanding that watching patients, to make sure they do not become unwell, is also acknowledged by the staff groups as a part of the care provided.

'Once you've got everybody organised there basically you are keeping an eye on everybody-watching that they aren't going to have a reaction' (Charlene, Registered Nurse)

'They (the staff) know I crash a lot so they keep an eye on me' (Sandra, Patient)

The staff acknowledged keeping patients safe is an important part of the care they provide; both the registered nurses and the clinical support workers identify that a

key part of their role is keeping patients safe and that the patients want this to happen.

'They want to know you care about them, they are safe' (Darcy Registered Nurse)

By making patients feel cared for, they also feel safe in the unit when undergoing their haemodialysis treatment.

The experience level of the staff was also something which made patients feel safe, as they believed they knew what they were doing.

'Feel more secure with them (experienced staff), cause they've been there a lot longer, so they know who you are and they know things about you, we know things about them, that makes you secure and can talk to them' (Emma, Patient)

The experienced staff included both the registered nurses and the clinical support workers who had been working in the haemodialysis unit for a significant period of time and were viewed as very experienced in the area.

As the patients know they are experienced, they feel safe. However, the patients do not comment on feeling unsafe due to inexperienced staff. One patient mentions that the new staff nurses who are learning always have a senior, more experienced nurse with them, so this may alleviate any negative feelings towards them; the senior staff are watching the inexperienced staff while they are working, which makes them feel safe. This is also part of a safe practice or procedure, which can allow the patients to feel safe.

Safe Practices or Procedures

Within the unit, the staff and the patients are aware of the checks which occur to keep the patients safe, and this is something that the patients look for from both groups of staff.

'Most patients seem to come across as being quite grateful for the fact you are checking on them' (Jo, Support Worker)

'It's all the way through, the procedures are there to provide the same level of reliable care, erm you know, cause otherwise they

would be pretty rubbish! Or making a detrimental impact on their wellbeing' (Jerry, Patient)

The patients understand the processes and what should occur and know that this keeps them safe whilst on their treatment.

'One'll (nurse) put you on and then somebody else will come back 10-15 minutes later to check your lines, check your machine and make sure everything is put in correctly and then they come back and these checks and you get your machine checked then' (Sandra, Patient)

During the interviews, staff mentioned the procedures and processes they carry out to ensure that all the patients are safe and that the treatment is correct. Different examples within the observations and fieldnotes also show different ways of how the staff conduct the safe practice and procedures.

The nurse makes the list, going round and checking all the machines 'double checking'



Figure 46: Staff checking the prescription and the machine

*'And then once everyone is on it's about checking everyone is safe'
(Jan, Registered Nurse)*

This fieldnote shows the procedure which the patient does not engage with and allows the nurse to continue what she is doing. By not engaging with her, the patient is showing they feel safe and know and understand what is happening.

'She gets up from the chair and goes to the first machine, she picked up the folder and looks at it- the prescription, and then flicks through the machine screens to check they are the same, she writes on the paper in the folder(the numbers) and signs it, the patient is reading his book and does not look up, she looks at the needles which are in the fistula, picking up the blanket that covers them to check position, to check for dislodgement or bleeding, and that they are correctly joined, she traces one with her finger, covers the patient's arm again and replaces the folder on top of the machine, and then moves on to the next patient/machine...'

'Staff are there, and protocol is that there is always one member of staff in the room and that sort of stuff, and you know that they may be out of vision, they aren't far away, there is always someone coming through the room, you are never far away from help, but yeah always feel cared for' (Jerry, Patient)

The 'protocol' that the patient mentions here is where one staff member is always in the room, and the rooms all link together, so people pass by and you can hear people are in the next room. This allows the feeling of safety through staff's presence in the unit. Figure 49 shows the floorplan of the unit and the way staff move around between the rooms. The checking of the patients and the machine was something which patients knew was performed by both groups of staff, both registered nurses and clinical support workers, and was expected.

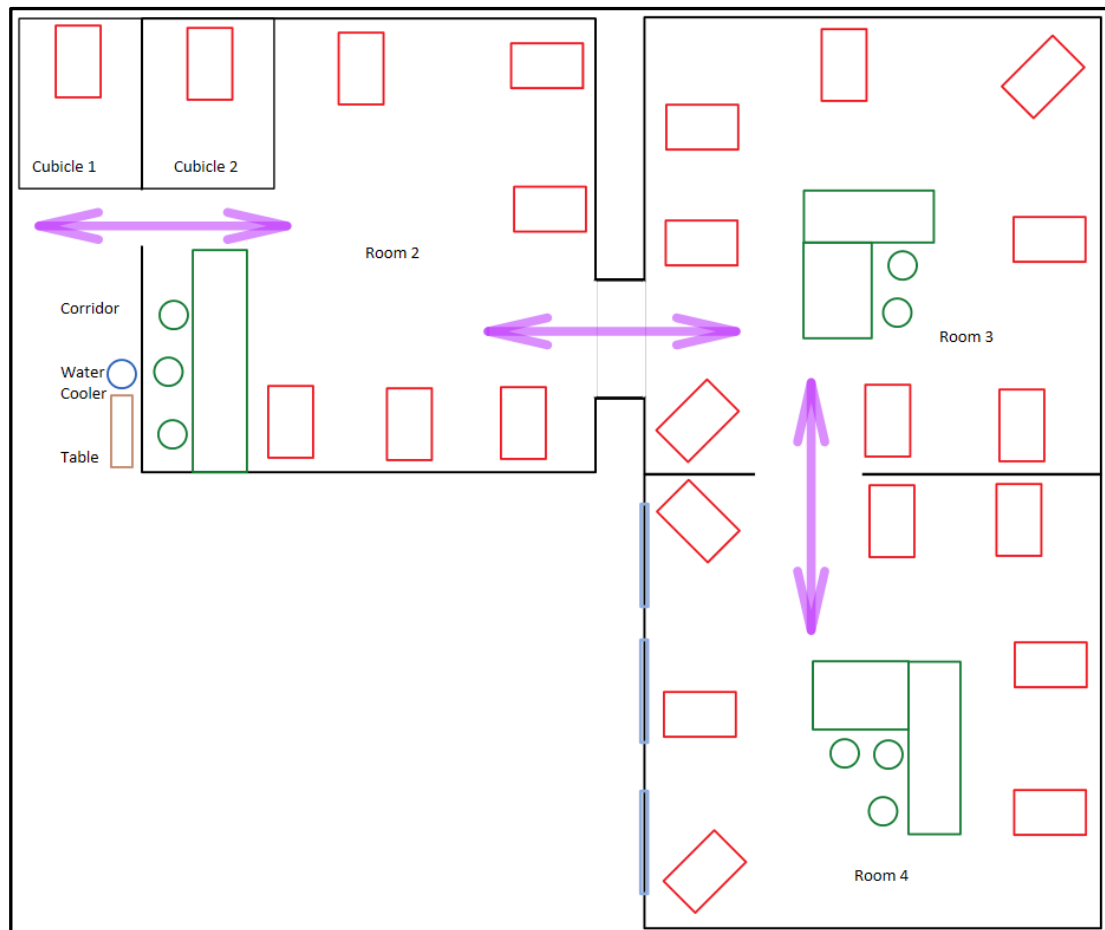


Figure 47: Floorplan showing the three main rooms in the haemodialysis unit.

The desks and chairs in each room (denoted in green) show the position of staff at the desks, with the red rectangles showing the position of the dialysis beds in each room. Staff are positioned where they can see the patients, and patients can see staff when they are in the room, either at the desks or with other patients.

The arrows show the access routes between the rooms, to highlight the ways in which staff and patients move through the rooms, which allows for patients to see staff and feel safe.

Summary

The feeling of being safe was something that patients wanted and valued and is achieved by both being in sight of the staff when on dialysis and the procedures in place within the area. The patients having an understanding of the procedures adds to their feeling of safety.

6.3.4 Summary- Elements of Direct Patient Care

Through analysis of the data collected through observations, fieldnotes, photographs and interviews - direct patient care was comprised of three key elements, being individualised, safe and comfortable. These three elements were shared across all three participant groups, producing a shared understanding of those concepts in this particular context.

6.4 Delivery of Direct Patient Care

When exploring and analysing the data collected from the fieldnotes, interviews and photographs, it was identified that there was a difference in the way direct patient care was delivered in the haemodialysis unit. Through the analysis of the research data, direct patient care has been reconceptualised and classed as being delivered in two different ways, either through either active or passive care, as from the data they are both distinct and not the same.

Active care is when the staff member and patient are together and there is some engagement or involvement between the two people. This active care is delivered in a variety of different ways in this setting, which Dani clearly described in an interview.

'We are prepping a patient for their treatment, putting them on their treatment, care plans, so doing their care plan with them, asking them how they have been between their treatments, are they, is there anything they want to tell me, is there anything they want me to pass on to the doctors, how they have been general, usually just generally chit chat and then giving them their medication, so things like quinine, doing all that, doing their Eprex⁹ or whatever they are called, and then taking them off and getting them ready to go home'
(Dani, Registered Nurse)

The other type of direct patient care encountered here is entitled passive care. This is when the patient is being cared for, but not actively involved in an activity or being engaged with. Passive care focuses on two distinct elements; availability and visibility, both of which are ways in which passive care is experienced.

⁹ Eprex is the brand name for a hormone - epoetin beta. It is used for treating anaemia caused by chronic kidney disease in patients on dialysis and is given as an injection into the dialysis lines when a patient is on haemodialysis.

Perceptions and Experiences of Direct Patient Care

From observations, photographs and interview data, this passive care was illustrated in various ways. Passive care occurred when the nursing staff checked the machine but the patient was not spoken to or interacted with, if when the nursing staff are at the desk writing notes but not doing anything directly with the patient at that point, or when the patient is sleeping and the staff are still within the haemodialysis room or area.

Direct patient care was carried out in the haemodialysis unit as either active care or passive care, but both of these allowed for the three elements previously defined which comprise direct patient care; being comfortable, receiving safe and individualised care and to be part of the care provided by staff in different ways.



Figure 48: Active and passive care occurring in a dialysis room

In the centre of Figure 48, using these two concepts of passive and active care are happening simultaneously in the haemodialysis unit. Active care is taking place through the nurse talking directly to the patient and the healthcare support worker is handing out a cup of tea to the patient.

Passive care is also occurring in different ways. One example in the above photograph (Figure 48) is the staff nurse sitting at the desk who is providing passive care to all the patients in the room.

Another example is the passive care provided to all patients in the room by the visibility and availability of the two staff members who are primarily actively caring engaged with one patient. Despite this, they are able to provide passive care for the others in the room.

Both of these new concepts will now be further explored in this section.

Considering the context or environment (see previous findings chapter), the registered nurses acknowledge that they are providing care for more than one patient when they are in for their dialysis treatment.

'We have four hours but in that time we are not only caring for that person, we are caring for others too' (Marty, Registered Nurse)

In a room with several patients receiving haemodialysis, the registered nurses and support workers will actively and passively care for all of the haemodialysis patients within the room and furthermore, across the whole unit.

6.4.1 Active Care

Active Care is the process or experience of care where something is actively happening between a patient and a member of staff, an engagement between the two or by direct contact or involvement.

Active care within the dialysis unit takes many forms and these were witnessed and highlighted in this research. Active care can be the act or process of patients being 'put on' or taken off the haemodialysis machine, the assessment for fluid removal, holding the fistula, or having a discussion or listening about treatment or external non-dialysis related activities.

The active care was seen in many different forms between the patient and either the registered nurse or the support worker.

‘Nurse’ Don (patient) shouts out. ‘what’s up? - oh you’re leaking’, she grabs a large square absorbent pad from a nearby trolley. ‘Has this happened before? I’ll clean you up, we’ll put some kaltostat¹⁰ under your needles’, putting the pad underneath the patient’s arm. ‘I’m going to get wipes, (she touches the machine screen and lowers the speed of the pump) I’ll get you cleaned up... and walks towards the trolley to pick up the pack of wet wipes at the side of the patient

kaltostat¹⁰

This fieldnote depicts an episode of active care, when a patient highlighted to the nurse there is a problem and she then assists. There is direct contact and engagement between them, initiated by the patient, who alerted the nurse to the problem with some blood leaking from his fistula, and the nurse continues in this active care by assisting the needs of the patient by stopping the bleeding and cleaning the patient’s arm area.

There is an engagement, either physical or verbal with active care, it is not the physical staff presence beside or nearby the patients or their dialysis space. There is clear involvement between the patient and staff, a two-way process or engagement.

‘Contact with the patient, talking with the patient’ (Julie, Registered Nurse)

Within the theme of active care, it will further be explained as either ‘time together’ or ‘verbal dialogue’. Both of these themes have a focus on a nurse and a patient being involved in an active process or verbal communication.

¹⁰ Kaltostat, is the brand name of alginate dressing and is highly absorbent. Kaltostat is used in this haemodialysis unit on a routine basis to stop bleeding fistulas and to promote clotting/scabs to form. In this situation it was put under the needle, where blood is leaking around the site in the fistula where the needle is inserted.



Figure 49: Active care from three registered nurses

Time Together

This is something which is viewed as both a necessity, and also at times, an unrequired and non-essential aspect of dialysis by both patients and haemodialysis staff. The staff, both support workers and nurses, acknowledge that some patients require more time or attention than others or want to talk to the staff. This time together is direct contact and engagement, either through chat, education or discussion about dialysis and fluid removal or assessment. Both the patient and the staff member are involved ‘actively’ in the exchange or encounter.



Figure 50: Registered Nurse doing a dressing

Figure 50 shows an instance where a patient was on dialysis and the nurse is doing a dressing on their hand. This is an example of active care as time together in the dialysis unit.

The importance of spending time with a patient in the dialysis unit was understood, as staff felt they may offer one of the few conversations they have that day, so they want to spend time with them, to provide them time with human contact and maintain some sort of relationship.

Staff sometimes make a conscious decision to spend that bit of time with patients and attend to their needs.

'I spend time with her coming on and off the machine, if she's awake I'll spend time with her, even in another room I used to make a point of spending time with her' (Angie, Registered Nurse).

This time with a patient is part of the care a patient can receive during their haemodialysis treatment. Staff spend time assessing patients within the out-patient unit, whether that is clinically in relation to the dialysis treatment or vascular access, or more generally enquiring how they are and how patients have been over the last few days.

'She'll sing you a song, she'll come over and see you, aye she's good' (Betty, Patient)

Within the dialysis unit there were different ways in which time was spent with patients when they are there.

'It doesn't have to be pulling up a chair and sitting for an hour, it can be five minutes, it can be ten minutes, it can be nothing' (Charlie, Registered Nurse).

The registered nurses spend time with the patients, usually when they were doing a clinical task, they would use this time together to talk to patients.

'Generally speaking, its either at the beginning or when they are coming to do the checks, or give me drugs or something, generally people don't stop and chat, unless they are coming to do something' (Donald, Patient)



Figure 51: Patient involved in the start of dialysis with two staff nurses-an example of time together at the beginning of treatment

'It's actually not necessary to be a brilliant nurse to be a good listener' (Marty, Registered Nurse)

The value of having time together and listening to patients is regarded as an important aspect of care in the haemodialysis unit, although this nurse does not regard it as part of being a 'brilliant nurse' (brilliant nurse was defined here as being clinically skilled and competent in the haemodialysis aspects of care).

Some patients are proactive in looking for time with staff if they want it, as one patient explained:

'I get enough time with them, 4 hours 15 minutes, if I've got anything to say I have enough time to say it' (Judy, Patient)

Patients do feel that staff give them time and attention during their dialysis treatment, although it is not always at the same time and may be later on into their dialysis session.

'They (staff) make time later in the session' (Rita, Patient)

'They give you their time which is good' (Betty, Patient)

This time together and attention is something given by staff to the patients and they are grateful for it.

Donald highlighted here that some staff would spend time with him chatting, but after they have finished their other tasks and jobs. Patients understood when there was time for chat and conversation and when this was not a possibility.

'If someone's quite chatty and they aren't too busy, they don't have other stuff to do, they will generally stand and chat' (Donald, Patient)

The time they spend together when on dialysis was a way of helping patients complete the treatment, and made sure they did not have any problems with the treatment itself.

'They (the staff) are willing to sit and talk, and help me, help me get through it' (Martha, Patient)

Time with the staff allows patients to cope with the dialysis treatment. They support the patients through issues related to the machine, physically and also psychologically.

One registered nurse recalled a patient whom she had spent a lot of time with when he was on dialysis to help with his education and understanding.

'Spending time with him, if he wanted to ask questions you gave him the opportunity to ask questions, you explained a little bit more of what he could eat and what he couldn't, give him a better understanding, he wanted to lose weight, because he wants a transplant' (Angie, Registered Nurse)

The time together when the patients were on the machine allowed for an opportunity for care to be provided to patients by the staff. To have time together, staff need to find or use an existing opportunity to do this with patients.

'So you have that bit of time before treatment, because they won't just get their book out before treatment, then the bit in-between, leave them to read their book, watch the telly, then you have after treatment, taking them off, you can speak to them' (Billie, Support Worker)

'Just for general chat, and doing the normal, erm, the blood counts, all the different, NeoRecormon¹¹ and things like that, the nurses are good- you can speak to them' (Edward, Patient).

The 'normal' care this patient mentions indicates that time with staff is part of their general routine, or the known process of dialysis care in the unit.



Figure 52: Time together talking - an example of active care

'I have spent a significant amount of time, not a lot of time, but with Cyril (patient), there are specific issues he struggles with' (Jo, Support Worker)

In this quote, Jo demonstrates part of the care that can be given to patients is by spending time with them, although 'not a lot of time' suggests that this is something that could be extended, or more time devoted to this part of care in the unit.

One patient, who was on haemodialysis for the second time after a few years on peritoneal dialysis at home in the community, felt there was more time now with staff when she was on dialysis. This was due to changes in the way of working and also because she knew what was happening and how things worked.

¹¹ NeoRecormon is a brand name for a hormone - epoetin beta. It is used for treating anaemia caused by chronic kidney disease in patients on dialysis and is given as an injection into the dialysis lines when a patient is on haemodialysis. There were two different brands used in the unit over the course of the research project.

Another patient identified that he felt there were more staff than there had been before.

'I knew what was happening, and there is more staff, there is more support staff, before it was in and out, in and out' (Edward, Patient)

Time together is usually dictated or led by clinical needs. One difficulty for the staff and patients is the overriding clinical or emergency aspects of care which will always take preference or precedence over all other ways of delivering care.

Preference is given to the physical dialysis aspects, such as the fistula or the machine. Staff will leave one patient to deal with something else, and not always get back to the patient to continue the delivery of the direct care that was already in progress through conversation or spending time with them.

'You are in the middle of a conversation with somebody and the only person in the room, and they are beginning to tell you something and then an alarm goes on another machine and you have to deal with it, you then lose that train of thought and the person doesn't say...'
(Marty, Registered Nurse)

Other things get in the way of spending time with the patient.

'But then somebody says oh can you do this and could you do the next thing, or it's my turn to stock up the trolleys- there is a choice' (Lee, Registered Nurse)

'Or you just know this needs to happen so you think yup patient might have to wait because some of it you can't hand on to someone else'
(Lee, Registered Nurse)

The different priorities or tasks which require to be done do impact on spending time directly with patients.



Figure 53: The Charge Nurse speaking to a patient during their dialysis

Time together facilitated patients being able to communicate with the staff. The staff being present and being able to talk to them made a difference to the patients' experience, but it was different for each patient.

'Being there, it's a different thing to different patients' (Charlene, Registered Nurse)

This idea of 'being there' as being something quite diverse for patients highlights the variety of things the staff require to do to care for the patients through their physical presence in time with the patient. It also has a focus on the different needs that patients have when in for their haemodialysis.

The time together which allowed for verbal communication was valued by patients. Patients feel that staff are willing to spend time with them to answer questions and explain their treatment to them:

'It makes a big difference, being able to talk to them, willing to explain things over and over again' (Martha, Patient)

Listening to patients was also a significant part of active care identified by both staff and patients.

'One of the staff said to me one day, how are you? And I said, I'm fine, and she looked back at me, and said you're not are you, and I just burst in to tears, so very quickly the curtains got whipped round, and she sat down and spent a long time with me, and once I was a bit calmer again she made me a cup of tea' (Rita, Patient)

'I think the important thing is, listening to patients, making sure that it's like a 2-way process, so trying as much as possible to involve the patient in their care' (Charlie, Registered Nurse)

Verbal dialogue or communication

From the data, verbal dialogue or talk was identified as something different to spending time together. Verbal communication occurred in various forms in the haemodialysis unit. It occurred when staff are with a patient, or when they are at the desk and they are raising their voices across the room to each other, sometimes when dealing with more than one patient at the same time.

'Direct patient care is the chats, which might be not always be that formal' (Marty, Registered Nurse)

The 'chats' was a way of providing direct care, but the acknowledgement that this was not always in this formal way aligns with the data from observations where these more formal chats were not as commonplace as the chats which occurred when staff were carrying out other duties.

'I think just having that chat with patients is part of your care' (Holly, Registered Nurse)

'I was sitting crying, and it was noticed, and they pulled the curtains round and spoke to me' (Donald, Patient)

One patient described that due to the treatment, it was difficult to chat to people while he was on dialysis.

'Nice to have someone to talk to, now that I don't feel so tired, at the beginning I was feeling pretty rough, now I feel better, chat doesn't bother me now' (Donald, Patient)

Several encounters were captured during the observations in the fieldnotes of verbal dialogue as a form of assessment by the staff, both nurses and support workers, relating to the pre-dialysis ‘numbers/observations?’

‘So how have you been since your last dialysis? - Registered Nurse

‘Your fistulas been okay? - Registered Nurse

‘How are you? - Registered Nurse

‘what’s your weight? How much you over? - Support Worker

One nurse felt the importance of chatting to patients, as they may not have many opportunities to chat to people when they spend a lot of time in the dialysis unit.

‘A lot of them never see anyone from when they see us, they might not see another soul in-between times’ (Angie, Registered Nurse)

Without the verbal communication, the staff know that they would find it difficult to care for the patient. Talking to the patients allows the staff to care for them.

‘You them start to build up a picture and an understanding of what goes on at home, what makes them tick, what gets them anxious, so you know then how to better, to better care for your patient cause you know much more about them’ (Holly, Registered Nurse)

One nurse acknowledged that it was the patients who dictated the verbal communication, but it allowed them to know more about them and establish a relationship.

‘If they want to talk- let them talk, that's how you find out about them and how their illness is’ (Angie, Registered Nurse)

‘You talk to them about their work, anything they like to talk about, talk about cars, anything they want to talk about, again, have a laugh with them’ (Billie, Support Worker)

Darcy highlighted that she wanted to speak to her patients, it was not just part of the job, but she also wanted to spend time with the patients when they were on dialysis.

'Cause I want to speak to them and see how they are, and see how they are feeling, and what's happening in their life and how they are feeling about stuff' (Darcy, Registered Nurse)

Nurses focus on family and friends, and not so much on physiological support.

'They will ask you, not so much how you are feeling, but how your sister is or how your dog is and things like that' (Edward, Patient)

This quote also suggests the lack of verbal communication around psychological support or time on this particular topic as part of dialysis care. Social conversation was highly used as part of active care with chat about family, friends and pets happening regularly. Despite the high level of communication that he has identified, Edward highlights the high active care, but also that it does not necessarily feature any psychological support.

The staff identified that verbal communication was important, and they needed to talk to patients when they were in the unit.

'I try to speak to all my patients on that day, I make a point of asking everyone one of them, even if I hadn't put those patients on, I would always approach them and say hi, how is that' (Charlene, Registered Nurse)

Speaking to every one of the patients during a shift was something which was done in various different ways, some staff spoke with particular patients at length, whereas sometimes the communication was much more minimal.

6.4.1.1.1 Banter

There was a high importance on verbal communication in the form of 'banter' from both staff and patients. Banter was described as a way in which both staff and patients had more friendly, light-hearted and informal conversations as part of their non-treatment related discussions.

'We have banter with the staff, I mean we even shout to them at the desk, you can shout to them and talk to them' (Sandra, Patient)

'Chat about whatever it is that's concerning them' (Lee, Registered Nurse)

'Getting to know your patients, what they want and what they don't want- having a banter at the same time' (Angie, Registered Nurse)

'Breaks the atmosphere, no use being sad, or moping about, it's got to be done, have a laugh while you are here, crack that joke, break the atmosphere, that's what it's all about' (Judy, Patient)

Jo identified that the banter they had with patients was not planned and was more spontaneous when speaking to patients.

'You tend to just sort of chat to the patients just sort of off the cuff, because that is just the way, just sort of the culture of the unit, the patients talk to you, and you just talk back and yeah' (Jo, Support Worker)

The staff in the unit keep the patients going, through the use of banter, whilst patients were on dialysis.

'It's just banter, talk about what we're gonna do at the weekend, basically that's it, I don't know, some of them talk about the machine, is it Angie? I've asked her two or three questions, she says this does that and this and that ken' (Jerry, Patient)

Banter enabled the patients and staff to also have a more informal side to the care and communication, and this allowed, for some, the use of humour.

6.4.1.1.2 Humour

Patients described the use of humour by both patients and staff as something that keeps them entertained when coming for treatment.

'They (the staff) keep the place going, keep you, it's not so much a drag coming in here, you get the ones who make you laugh' (Sandra, Patient)

'They lassies can have a laugh just as anyone else, suppose they have to do something like that, keep us happy, take your mind off the needles getting shoved in' (Judy, Patient)

'Having a bit of a laugh with them (patients)' (Darcy, Registered Nurse)

'They come in, have a laugh with them, make them forget for five minutes' (Lewis, Support Worker).

Lewis used humour and ‘having a laugh’ to normalise the situation and make the patients feel less like patients.

These are examples of humour observed in the haemodialysis unit, from patients and staff as examples of active care.

‘how was your holiday?’ Paul (support worker) asks, as getting patient comfortable on chair with pillow positioning, ‘full of Irish people!’ ‘haha!’ The patient replies

‘I’ve not seen you for a while’ the nurse says to the patient, ‘you put me on 2 weeks ago’ he replies ‘you did my dressing’. ‘well I bet I made a good job of it’ she says! ‘nope’ he says, they both laugh’

Patient has a bleeding fistula after the needles have come out, there is blood on the pad under his arm. It’s taken a while to stop bleeding but it now has. The nurse comes over to put the plasters on, and the patient says ‘you do realise my arm is empty now!’

Humour was something which was not used by all staff and patients, and patients knew who they could and could not joke with as part of the dialysis experience.

‘Cause there are one or two people that you shouldn’t joke with cause they don’t get the humour’ (Jerry, Patient)

6.4.1.1.3 Communication led by patients

Rita talks here about using the staff as an emotional support, she can talk to the staff about her kidney disease and treatment and how she is feeling.

‘Think it’s good sometimes, to talk to somebody who’s not, emotionally effected by it, they are not part of your family, so they can listen to, and I don’t say not care, maybe shrug it off slightly, it doesn’t, they care for you, they give you help and advice, but it’s not going to weigh them down with it afterwards, I would think, they might think about it but they can get on with their life’ (Rita, Patient)

Staff identified the importance of speaking to patients, but that they will take the lead from patients and how they are feeling, which dictates the communication at that point or on that day.

'The minute you chat to a patient before treatment, it takes their mind of it, gives them that option to have banter back with you, lighten them up a bit, make their treatment a bit easier, if they don't watch telly, dinny listen to music, staring into space, you are going to want to speak to them' (Billie, Support Worker)

Charlene here identified that the patients did inform her when

'Usually you find if there is anything they want to tell you, they'll tell you it and you'll say how are you doing, how are you feeling' (Charlene, Registered Nurse)

6.4.1.1.4 Brief verbal communication

As some of the haemodialysis care is similar every time, and the patients understand what is happening, the discussion between the staff and patients can be very minimal and with a clinical focus.

'Shallow or deep?'

'what angle?'

'12 o'clock and shallow?'

'tell me what the angle is'

These four examples from the fieldnotes show questions asked by nurses to patients all of which relate to nurses cannulating the fistula. The responses were brief from the patients, and that was where the communication ended, whilst continuing with inserting the needles and then taping the needles in place and then checking their patency with a syringe.

Despite this apparent brief communication, staff are still spending time with the patient and putting their needles into their fistula after the communication.

'I'm never four litres over!'

One patient exclaimed this when he arrived in the unit for treatment, before any staff had spoken to him. This comment is in relation to his weight and suggests the

volume of fluid which required to be removed. This situation led to the patient suggesting the scales were wrong, as he was not in agreement that this was the case.

A conversation between a nurse and patient, the patient is on the machine and treatment has just started.

Registered Nurse: 'tape?'

Patient: 'round the wrist'

Registered Nurse: 'that's it'

Patient: 'smashing, thanks'

She then walks away from the patient.

Some staff identified that patients did not always want to spend lots of time with staff and sometimes would not engage with them as much as other times.

'They want to come in and do their treatment and, well, don't seem to, I'm not saying they don't, they don't seem to want to speak to you' (Dani, Registered Nurse)

6.4.1.1.5 Summary of Verbal Dialogue or Communication

Verbal communication is one way of providing active care to patients, both with a clinical focus or with a friendlier focus. Both allow the patient and staff to develop a relationship together, to allow for care to be delivered and received in the haemodialysis unit, however it can be very minimal.

Active Care is a requirement

Both patients and staff know and understand that active care, as time together or verbal communication, is something which is a necessity as part of the job or haemodialysis process.

Staff found it difficult when they needed or wanted to spend time or care for more than one patient.

'Although sometimes that's difficult when there's another two or three you think I really need to be there' (Lee, Registered Nurse)

Patients view staff spending time actively or directly with them as an expected part of their treatment. Patients have suggested time with staff is a necessary part of the nursing staff job or role within haemodialysis.

'She (the nurse) was doing her job, making sure I was alright' (Rita, Patient)

'They're all entitled to your time, some days we can't cause we are busy, but most days in that hour (the lull) you can' (Angie, Registered Nurse)

This is echoed by the patients who also feel that sometimes they need the staff, particularly if they are new or unwell, and then as they become more stable on dialysis, they have less need or requirement of time with the staff.

'Time with nurses it was extremely important, but eh, you know, the way the staff are set up, is that they do devote more time to newbies' (Jerry, Patient)

Patients wanted active care or time with staff, both the registered nurses and the clinical support workers. Despite having other clinical tasks and duties, patients felt that staff would find time with patients.

'Always finding that bit of time with you' (Sandra, Patient)

Patients felt prioritised in getting time with staff and viewed this as important part of haemodialysis or care.

Time with staff where patients could talk to them about their dialysis, or disease, care or treatment was something which patients wanted and this did occur in the dialysis unit.

Time with staff allowed patients to get information when they wanted it, they could use the staff when they were there to answer their questions.

Time with the staff provided support to the patients when they were on dialysis, to help come to terms with what was happening.

'The people who had experienced it themselves, or a close family member, were more understanding of what I was going through, yes, they were more understanding, some of the others were very

sympathetic, but because they hadn't been through it themselves, they didn't quite understand what it was' (Rita, Patient)

Lack of Active Care

Staff do understand if patients don't want to spend time with them, but they feel that patients are missing out on something that could be provided by staff.

'I think that's just them to be honest with you, I think they could probably do with somebody else, but that probably just their way to kinda dealing with it really' (Lewis, Support Worker)

Charlie identified that some staff also do not focus a lot on spending time with patients in different ways, as they have a more clinical focus to their time with patients.

'It's about putting them on and taking them off, and there isn't an awful lot about the social side, the psychological impact of someone coming in to a dialysis unit, some are so focused on getting the task done, they miss out on, to my mind, the really important factors' (Charlie, Registered Nurse)

Active Care can be minimal

Despite the claims from the participants that there is not enough time with staff and patients together, there is also an agreement from all three groups that sometimes there is not always a requirement for time to be spent together.

'I think they just respect people's privacy, I've got my headphones on, watching my iPad. Other people are sleeping. So staff are just respectful, once you are on this you just want to sit, sometimes sleep, sometimes I'm just too tired to sit and chat (Donald, Patient).

Both staff groups acknowledge that patients do not always want to spend time actively with staff, with both groups having other things they want to do or should be doing.

'Some people might just want to come in, put their headphones on and have peace' (Charlie, Registered Nurse)

'I would probably just have a little chat before treatment and if, again if it's patients that you know, that like their telly, that like reading their books, that like that little bit peace and quiet, maybe that's just their time, maybe they don't get that at home, ...you can't force them

to chat to you, if they want to read their book it's fine' (Billie, Support Worker)

The prospect of forcing someone to spend time with them or making them engage with them is an idea with that staff do not push. The support workers did not feel as comfortable to force or push, whereas registered nurses did identify they may have to encourage conversations when necessary.

Staff recognised that some patients do not want to spend a lot of time with staff.

'They don't want to spend a lot of time with us, because most patients, they prefer to watch the telly and play their games, and maybe they don't want us to chat to them without any particular reason' (Julie, Registered Nurse)

'Where you can kind of gauge they are up for a chat, but there is no magic formula, someone's heads deep in a book, I'm not going to take it off them and say it's time for your chat!... some of them just want to come in and sit and read their book or watch a film and they don't want to talk to staff' (Charlie, Registered Nurse)

The patients also suggested that they know that they cannot always have time with the staff, as they know they have other tasks to carry out and did not want to take up all of their time.

'They (nurses) are busy, they have other things to do, their paperwork and that, I don't want to keep them back' (Judy, Patient)

'Not that I don't want them to disturb me, but I feel they don't need to keep asking me for things' (Charlene, Registered Nurse)

One patient did not want to talk to the nurses about their concerns or problems, and did not use the nurses for this when coming for dialysis.

'I like to keep it to myself, don't let anyone know my business, don't want anyone else to worry about it...I just don't believe in anyone knowing your business, I'm a private person' (Judy, Patient)

Some patients do not want active time with staff, as they use the time in the unit when receiving treatment for them to sleep or relax, to catch up with TV and other things.

'(time on dialysis) I use it as my unwind time, I can read, I can sleep, I can catch up if I'm tired when I come in, you get your tea and toast which is brilliant, tea and toast which I enjoy, whereas at home the phone goes or door goes, so I use it as my free time, and I can just relax, if I want to sleep, read or just look at the walls, that's up to me, listen to the telly, listen to music, so I use that time for me' (Emma, Patient)

Summary of Active care

Active care is one way in which direct patient care is provided. It can be as time together between a staff member and the patient, but when the focus is on the patient and the patient is involved in some way. Communication between a staff member and a patient is also a way of providing active care.

Particularly in the haemodialysis unit, there are differences between patients in how much active care they feel they require or want, and staff acknowledge that active care is sometimes more clinical task focused.

6.4.2 Passive Care

Passive care in the dialysis unit occurs when staff members, both registered nurses and support workers, are in the room along with the patients. However, nothing is actively happening between them and there is no engagement between them.

The two themes within passive care are the physical visibility of the staff and also their availability, both allowing the patients to feel cared for despite not dealing with them directly. There are also the sounds of passive care that also indicate the staff presence in the room and suggest the visibility of the staff, through the noises made by them in the dialysis unit.

Despite staff looking after others, patients still felt cared for in this situation.

'So I didn't feel abandoned even though they were dealing with another person in the room' (Donald, Patient)

This fieldnote from observation 3 shows different examples of passive care, where the patient is present but not involved in the discussions or acknowledged. Within this example of passive care, the staff view that whilst they may be in the room, sometimes the focus can be less on the patient and more on the equipment.

Observation 3

'Taking 2.7 off today, that okay Mr Massey?' said Julie the staff nurse to the patient, whilst looking at the machine, at the screen and touching the screen, putting in treatment information, she doesn't look at him, the patient says nothing 'let's do your blood pressure', Julie presses the button on the machine but the cuff doesn't inflate, the blood pressure isn't working, there are 3 staff nurses talking about it at the side of the patient, beside the machine. They are trying to fix it. They are not talking to the patient, he is just sitting, not saying anything. Staff nurses are talking, discussing the patient and what they are doing – fluid removal rates- but not involving the patient or even looking at him, they are looking at the machine, and the folder, and the equipment, and sorting the trolley and blood pressure tubing and cuff. The patient is now reading his iPad- arm outstretched with the cuff on

'The focus can be utterly on the machine' (Darcy, Registered Nurse)

Whilst this could be something which feels impersonal, the patients did not feel the machine was the focus of the staff at all times.

'Once the machine is set up, unless they are putting someone through their paces, that's the only time, they usually tend to tell you what's happening anyway, whether our pressure of the IV drip, or whatever, they are usually quite good at telling you what's going on' (Donald, Patient)

Despite this, the patients feel that the staff being visible and available allows for a feeling of being cared for.

Staff being Visible

Staff being in the room, whilst the patients are on the machine, is viewed by patients as a positive experience of care. They feel their presence shows that they are being cared for, although not in a direct, active or engaged contact situation.



Figure 54: A nurse checking the machine

This image shows a nurse checking the machine, while the patient lies asleep in the dialysis chair during treatment.

'Just in case your machine starts ringing off, and you're like oh what's going on, there always is (someone in the room)' (Donald, Patient)

The patients acknowledge the staff being present and 'keeping an eye' allows them to feel safe and cared for.

'Just keeping an eye on the machine, keeping an eye on my needles, that they are still intact, and they are firm, with the tapes, we have had those problems in the past, especially if I fall asleep, that somebody is keeping an eye on me, and I feel quite confident that they are' (Emma, Patient)

This patient indicated the staff being physically visible or present is important, allowing them to ensure the completion of dialysis with no complications or problems.

'They are there to, to make sure I, that I have no problems' (Judy, Patient)

However, one nurse comments that being at the desk, at a distance, is not providing good quality care.

'Some people do just sit about, and hope nothing goes wrong for the next 4 hours before they come off, which I don't think is a good idea of care' (Jan, Registered Nurse)

'Some patients just want to be left alone, which is fine by me but you kind of have to use their own judgement to determine whether that is the case or not' (Jo, Support Worker)

Two staff nurses, Margaret and Karen, are sitting writing notes at the desk in room 3. They are writing in the patient folders from the morning shift, all the afternoon patients are on their machines, haemodialysis has commenced, and patients are occupied with magazines, tablets, the TV or sleeping.

Sandra likes that the staff are in the room when she is on the machine.

'They don't have to come and physically sit down and blether to you' (Sandra, Patient)

'Most of the time they're in the room anyway, so they tend to come round and ask how you are in general' (Barbara, Patient)

The patients know the staff are always in the room and will spend time with them as part of their activities in the room.



Figure 55: 'I'm on the phone'

The nurse in Figure 55 was on the phone during the observation. She was talking to staff in another room, as she could not leave the room to go and speak to them face to face. She could not leave the room as that would have left the room unstaffed.

6.4.2.1.1 Sounds of passive care

The sounds of care occurring, or staff working is an aspect of passive care. Particularly during the ‘lull’ period in the shift, where staff are more focused on tasks carried out at the desk, the cleaning of equipment or preparation for the next group of patients, the sounds of the unit became apparent. These sounds of the machines, staff typing on the computer keyboard, the phone ringing and telephone conversations, or the sound of staff educating each other all maintain this feeling of passive care, due to the staff presence and activity, although they are not actively caring for the patients.

The machine ‘bing bong’ sound elicits a response from the staff, both registered nurses and support workers, where they will move or gravitate towards the machine, sometimes fast and sometimes a bit slower, and sometimes whilst still maintaining the focus on what they were previously doing i.e. maintaining a conversation with another staff member

***There was sometimes a hierarchy to who would respond, if there is a registered nurse there, the support workers will sometimes look to them to make the first approach, or ignore it for the registered staff to deal with without acknowledgement.*

All of these sounds, and the silencing of the sounds, identified that staff are carrying out activities that formed different aspects of care.

The sounds of the staff at the desk talking, answering the phone, or fingers hitting the keyboard allows patients to hear they are present, despite the staff not directly delivering active care to them at that moment.

Staff being Available

The availability of the staff, to react if needed, is vital to the patients. This availability is important to patients when they are receiving treatment as the understanding is that the staff will react and are able to go and provide direct care.

The staff being in the room allows them to feel cared for and safe even when they are not doing anything actively for the patient.



Figure 56: One patient on haemodialysis while the nurse prepares the other dialysis space

Figure 56 shows passive care where one patient is on the dialysis machine, and the nurse is preparing another dialysis space for a patient's arrival for treatment.

The nurse is in a passive position but present and available, should she be required by the patient as the nurse is not focused on the patient at this moment.

'You aren't isolated, you aren't being left' (Jerry, Patient)

Patients want the staff to be present, and they feel they are keeping an eye on them, even when they are not directly visible to the staff. One patient felt that the buzzer system allowed the staff to be alerted if they required assistance, but their presence to allow them to react to the buzzer was enough.

'You know that if you need assistance, you can always push the button and someone will attend' (Jerry, Patient)

'Being there if they need you' (Charlene, Registered Nurse)



Figure 57: Two nurses talking at the side of the patient

Passive care is shown in Figure 57, where two staff members are talking and one is discussing and teaching the other beside the patient. The patient is not engaged with in this occasion but their presence and visibility highlights that they are available, should they be required.



Figure 58: Staff at the desk writing notes

Despite the patients not always wanting active care at all times when receiving their dialysis treatment, the patients do want the staff to be available to them if needed. Figure 58 shows the staff at the desk writing notes while the patients receive their treatment. Again, the staff here are focused on the task of writing notes and not directly focused on the patients who are receiving treatment in the room.

'There is always someone at the desk if you don't feel right' (Edward, Patient)

'You aren't in their eye line all the time, but they are aware of you being there' (Rita, Patient)

'If you needed them they'd be there' (Rita, Patient)

'I can always see what's going on aye' (Bob, Patient)

The dialysis rooms are mostly open spaces with the desk in a central position so if staff are at the desk, they are still prominent in the room. The cubicle spaces however, are slightly different. Being out of sight of the staff is something which the patients did not enjoy as they could not see the staff.

'I don't feel secure in the cubicle' (Sandra, Patient).

The physical presence and visibility of the staff despite not doing anything directly for or with any patients still provided a feeling of safety and comfort through the presence.

Observation 2:

*****I'm sitting at the desk, I can't make out what the staff are saying behind the desk, they are chatting, all looking at each other, sort of sitting in a circle. The patients are all round the outside of the room. I can't hear the staff conversations, and the patients are silent. I can hear the machines whirring, and gurgling, but not much else.***

In this fieldnote, the patients were on dialysis, and the staff were sitting behind the desk talking to each other.

One patient commented within an interview that the staff being in the room was hugely important.

'It's comforting in a way, if something went wrong, if no-one is there it can be quite painful or worrying.... No matter what they are doing they will come across, come across and take my blood pressure, put me back, lie back' (Edward, Patient)

During the observations, there were periods of silence when the nurse and patient were together, but not engaged in tasks or conversation. This was during clinical duties or when waiting for a trigger for care e.g. the machine being ready or treatment to complete.

Silence between the nurse standing at the side of the patient and the patient who is sitting in the chair, nothing is being said. The nurse stands with her apron and gloves on, and the patient sits in the chair, both waiting for the machine to alarm and break the silence between them.

There is also a presence felt by the staff being in the room whilst patients are receiving treatment. This can provide many an opportunity for direct care.

'Time to say anything, the nurses are there all the time' (Judy, Patient)

'Assistance is always available' (Jerry, Patient)

Staff working together, seen to be working together and helping each other also made patients aware of staff working and being in the room.

'Passing, going back and forth, and they do help each other out' (Martha, Patient)

Whilst patients were on dialysis, or receiving treatment, most kept themselves busy or entertained or distracted with books or the television. However, when staff approached them to do a clinical routine procedure or task, they would give the staff their attention, and look for interaction from them when they were at their side.

Staff is at the patient's side, doing a check, staff member (registered nurse) has the folder in their hand and appears to be checking the prescription and the machine are the same-standard procedure in the checking process. The patient has been sitting in the dialysis chair, with their headphones on and reading their book. As the nurse is doing this, the patient takes off their headphones and puts the book on the table in front of them.

This notion of passive care requires the staff to react to an alarm or a patient requiring something, and when there is no reaction the patients do feel uncared for.

'I don't feel unloved or abandoned!! you know, eh, actually that happened in a ward, and occasionally the alarms would be going off, and no one would come, I think I waited 2 hours' (Jerry, Patient).

This quote from Jerry, contrasts the dialysis unit with his stay in a ward, where he did not see staff and they did not answer the alarms.



Figure 59: Writing Notes

Whilst providing care for patients, staff are focused on the other staff members in a

teaching and learning capacity, educating newer or junior staff on dialysis and practices. Staff are shown in Figure 59 to be writing notes whilst patients are on dialysis. By doing this, passive care is in progress as the patient can see the staff, and is feeling indirectly cared for due to their presence and what they are doing, whilst not being engaged with by the staff.



Figure 60: Focus on teaching staff, not the patient

Observation 3 (Links to Figure 60)

Staff Nurse Jean, is putting on a patient. The machine is between them.

There is a nurse who is learning is beside the Jean, furthest away from the patient. Jean is telling her about the machine, Jean then asks the patient about the position of the needle she is about to insert into the patient's fistula. Jean then turns her attention to Karen the new staff member again, telling her how to put a patient on or initiate dialysis, she says nothing else to the patient.

Robert is just sitting with his arm on a pillow while Jean talks through Karen what she is doing.

The following fieldnote from observation session 3 shows an example of staff chatting to each other whilst carrying out clinical tasks and the focus was between the staff in the engagement and conversation, while the patient was getting commenced on dialysis treatment.

Observation 3:

There is only one patient left to go on the machine, he is already in the room, on his chair (patient in space 6- Lucas),

Elaine is going over to him with the BP machine, 'what was your weight?'

Samantha is with another patient, - 'do you want this at your side Eddie- yes please'. 'you don't normally take fluid off do you?' he nods.

Elaine to Lucas 'how is Lucas today?' okay? He nods in reply to her. Samantha is now setting up the trolley and Elaine is setting up the machine, whilst Lucas is on the dialysis chair on his tablet computer. Samantha and Elaine are chatting at the side of the patient, beside the machine. Samantha is asking about what time Elaine is finishing today, as she is on a half day. They are chatting about Julia's wedding at the weekend, and guest list and seating issues, Samantha is cleaning the patient's permcath, whilst continuing talking to Elaine, who is standing at the machine. Lucas is still on his tablet computer.

***Putting a patient on the dialysis machine is a procedure with 2 people, so one is handling the clean permcath and the other is handling the machine and lines from the machine.*

Samantha - attention back to the patient, you're not diabetic? No, 'Is it always reversed?' 'Ye's, Samantha then turns back to Elaine and continues to talk about the wedding, they are laughing, attention is then back to Lucas 'we'll do a dressing change today'. The patient is now connected, he gets comfortable on the chair and pull his t-shirt down. Elaine 'I'm just giving your tinz¹' the patient looks up in an acknowledgement, but does not verbally respond to them.

*** Lots of things happening, patient wasn't engaging back to staff so staff then didn't include him in anything.*

¹² Tinzaparin or Tinz is the medication used as anticoagulation for the dialysis treatment, this is injected into the lines of the machine once the patient has started treatment.



Figure 61: Writing notes and stocking trolleys

Figure 61 shows the staff doing other jobs, the nurse in the foreground is writing notes and the support worker behind is stocking and cleaning the trolleys. A patient is behind them both on the dialysis machine.

Summary of Passive Care

Passive care is the staff presence in the unit and this allows the patients to be indirectly cared for through their visibility. Just by being in the presence of staff, there is a feeling of being looked after.

6.4.3 Moving between Active and Passive Care

Patients understand that staff have to care for others, but they still feel cared for during when they are not being directly attended to. Staff can move between providing active and passive care, or by providing active care to one, their presence in the room, although with another patient, can allow passive care to occur.

By actively caring for one patient, the staff are passively caring for others, while they are within the same room. A relationship can be established and maintained by the staff caring for others as the patients can see the staff working.

'At the same time they're getting other people off as well but they're always keeping an eye on you' (Martha, Patient)

'Although sometimes that's quite difficult when there's another 2 or 3 you think I really need to be there, I need to, you know I'm trying to and that's the phone ringing again, ah give me peace' (Lee, Registered Nurse)

When patients are newer on treatment they identified that they get a lot of active care from staff.

'(Staff) they devote more time to the newbies, to get inducted, and as you become more experienced you get left alone a lot more which is fine, you know, quite happy not to be interrogated all the time!' (Jerry, Patient)

The amount of active care which staff provide to patients can be dependent on the patient and how new they are to dialysis treatment or the out-patient area. The newer patients, particularly the ones who have 'crash landed' into dialysis with renal failure may need more active care and support than some of the more established patients.

This section of fieldnotes depicts a member of staff spending time with the patient, but not always carrying out any care to the patient or continually engaging with him through conversation.

Justin is on the machine, and having a social conversation with George, a Staff Nurse, about both their weekend plans- football watching and different teams. George is standing with his arms crossed, then looks and begins to touch the machine, the conversation is maintained by Justin, but not quite by George who is, I think, reprogramming the machine, touching and pressing buttons on the screen, he is vocally responding but looking at the machine. He is looking at the machine and touching the screen- but verbally responding to the patient showing he is listening and engaged. George then stops touching the machine and goes back to talking to Justin, leaning on the machine beside him and chatting about the games they will be watching at the weekend.

***I later found out that George was looking at the blood volume monitoring or BVM, a measurement to help display if the patient has fluid on board or not, and was trying to increase the fluid goal for removal during this conversation...this was not discussed or explained to the patient, during my observation*

This sitting down and talking to the patients, when not carrying out another task, was something which did happen during the observations.

The administration of medications is an activity which involves the patient and the registered nurse, but is sometimes part of active care, where there is communication between the two and at other times, it is a passive care situation where there is no interaction between the two, despite the close proximity for a period of time.

From Fieldnotes (following observation 9)

***The administration of Intravenous Iron supplements is a task where the patient has the registered nurse beside them for the 5 minutes in which the drug is administered into the blood lines through the machine. There is a huge variation between what happens during this 5 minutes. Some staff take a chair over and sit down whilst administering, I have seen one nurse who positioned herself behind the machine, so that they could not see the patient whilst administering the medication into the machine, and sometimes there is a full 5 minutes of conversation and then beyond the activity. There is usually an acknowledgement from the nurse to the patient to suggest that they will be administering the medication but when the nurse is doing this, some patients don't even take their nose out of the crossword book or iPad.*

6.4.4 Summary of Delivery of Direct Patient Care

Direct patient care is delivered through a combination of active and passive care.

Both of these ways of delivering direct patient care allow the patients to feel individual, safe and comfortable. Through active care, this relates to the active engagement and time with staff, and with passive care it is about the availability and viability of staff.

6.5 Connections in the Haemodialysis Unit

One important part of the delivery of direct patient care, in both active and passive care, is the relationships between the staff and the patients. The patients rely on people they see when they come for dialysis, and the relationships they have made with both staff members and other patients. An important aspect of the care provided is down to the relationships developed in getting to know the people around them.

Patients enjoy coming to dialysis because of the people and the relationships they have there;

'I felt like I'd just be stuck at home' (Barbara, Patient)

Dialysis in the hospital makes them feel less isolated. When faced with the decision of either home dialysis or in hospital haemodialysis, some valued coming in to the hospital to interact with people, both other patients and staff.

These relationships can be individual, between a staff member and a patient, or as a group in the whole room together, but whoever the relationship involves;

'It's a connection, and it's nice to have that with someone' (Marty, Registered Nurse).

Patients do care about the nurses and other patients and what they think of them, and this quote from Sandra highlights the importance that patients put on the staff and patients and the relationship they have with this group.

'I could say right I'll no be back, what's folk gonna say, what's the nurses gonna say' (Sandra, Patient)

This theme is split into the individual connections, group relationships, and boundaries in relationships and how a connection is maintained.

6.5.1 Individual Connection

The unique connection between a dialysis patient and the members of staff who work in the area was highlighted by the patients and both of the staff groups. There is a particular interest in the person who puts the patient on and takes them off the machine, as this is a key part of the dialysis treatment in this unit.

'Dialysis is a very delicate thing, it's between the person who's putting you on and you' (Betty, Patient)

There is an importance placed on the relationship between a single staff member and a dialysis patient, but it can vary, due to both parties involved. The people and their own personalities has an effect/impact on the type of connection or relationship between them.

'Relationship depends on the nurse, and the patient, their personality' (Charlie, Registered Nurse)

Developing a relationship or connection with the patients is important and something which both staff groups want to achieve, value and will actively try to achieve.

*'I will try my hardest to kind of build up a relationship with patients'
staff (Lewis, Support Worker)*



Figure 62: Nurse and patient talking together

*'Getting to know them (patients) is an important part of the job'
(Marty, Registered Nurse)*

This quote highlights three of the four aspects of the individual connection in the dialysis unit between nursing staff and patients.

'If you build a rapport with patients and they become familiar with them, they'll trust you to tell you if they know you are going to do something about if they have an issue about something' (Charlene, Registered Nurse)

A patient arrived into room 2. He says to the clinical support worker who was at his allocated space, 'I'm well over today- don't think I'll manage to take it off.'

This section of fieldnotes indicates the expert patient knowing the procedures and

what they can tolerate, but also showing the focus on the dialysis and its procedure, as the patient did not say hello to the staff when he entered the room. This shows an existing relationship and potential familiarity with the staff that he did not feel required to say hello, and was straight into the routine or learned behaviours; he knew what the procedure was, and that the weight/fluid removal was important.

Familiarity

There is an importance held by the staff and patients of knowing each other and being familiar with each other.

Patients knowing the staff in the unit is an important part of their care experience.

*'It's usually the same staff, I like that, I like the continuity of it, and they also get to know your fistula as well so that's good as well,'
(Barbara, Patient)*

During observations, lots of patients and staff members were having conversations about non-dialysis topics. The conversations highlighted that the patients were people and the staff had lives outside of work but also indicated that both parties involved in the conversation knew each other and had some knowledge of this prior to this particular conversation.

'Over time you do, you get to know them' (Dani, Registered Nurse)

Staff know that they become familiar with the patients, due to the time that they spend together in their attendance for treatment.

The support workers, as well as the registered nurses, became familiar with the patients, and knew when they were behaving out of character or unhappy.

*'When somebody comes in and you can just tell they aren't happy'
(Billie, Support Worker)*

The familiarity between the staff and patient groups was seen during the observations.

*Susan (patient) asks 'did you have that meeting about the meal'
Charlene (staff nurse) is planning her wedding, and Susan is
enquiring about the latest developments.*

*Nicky to patient Steve, in the preparation stage before needles
inserted 'You up to anything nice yesterday?' she referred to his
'day off' dialysis, 'nope- did you get out to the garden?'*

**She is showing the existing knowledge and familiarity of this
patient's usual day off plans and his likes.*

These examples from fieldnotes show that both the staff and patients would initiate non-dialysis conversations during a variety of times; during clinical tasks, when staff were nearby and also with staff going over to patients to continue a conversation that they had started previously, either from a previous dialysis shift or earlier that session. These all demonstrate the existence of a previous communication or relationship which has been established or developed prior to this conversation.

The nurses acknowledge the importance of getting to know the patients and also sharing information about themselves, which helps the patients to feel more comfortable.

*'Introducing yourself, finding a little bit out about them, do they
work? Can they work? And just telling them a little about yourself,
I've worked here for seven years, never be afraid to ask us a question.
kinda puts them at ease' (Angie, Registered Nurse)*

The familiarity was a surprise to Donald, who over time had established the staff as people, not strangers.

*'Unexpected, and very important, I didn't realise I would get to know
people, when you start off they are all strangers, you don't know who
is who, but then you get chatting to people' (Donald, Patient)*

The importance of knowing the staff and them being familiar to him was something he valued.

Patients want the nurses to be familiar with them. Having staff who are familiar to the patients impacts on the care and the feeling of being cared for. It also allows for still having the familiarity from the staff, when the patients are in a different room and not with their own regular patient group.

'You know all the faces, you know all the names so when you do go into another room you know who's dealing with you' (Sandra, Patient)

One patient in particular described the staff knowing him as a person as being an important factor in his care and that he enjoyed this.

'It's good when the same people crop up time and time again, cause they know your fistula, they know your habits, they know not to interrupt' (Jerry, Patient)

Staff also value familiarity. They feel it allows them to care for people when they know them better.

'It's easier to care for patients you already known for a while, cause the new patients don't have such a detail information about their social life, problems, mental state, past medical history, so we need to educate ourselves on this matter first before we attend any care' (Julie, Registered Nurse)

When staff are familiar with patients, it can help them to establish if something is wrong with a patient, due to changes in their behaviour or disposition.

'Especially if it's somebody that I know I have banter with, who I have a laugh with usually, so if they aren't that person I know there is something wrong' (Lewis, Support Worker)

Staff become familiar with the patients by caring for them, getting to know the patients because they are in the room, through both active and passive care.

'You get to know them (patients), by putting them on all the time, that's kind of sometimes difficult, putting them on or taking them off, being in the room, generally' (Dani, Registered Nurse)

The familiarity can also develop through the patients witnessing the different members of staff with other patients and how they are acting, working or caring for them.

'Seeing the way they work, you can see them with other patients as well, seeing how they work, how they speak to people, if they are asking questions about things, they understand enough to give you the answers back that you want to know' (Rita, Patient)

There was an understanding that it took time for familiarity and a relationship to be established between the patient and the staff member.

'Over time you do, you get to know them' (Dani, Registered Nurse)

A relationship was not instantaneous, due to the lack of familiarity.

'It took me a while to get used to the faces and names' (Martha, Patient)

'We gain confidence in the new ones (staff) as time goes on' (Emma, Patient)

Watching the other staff and patients allows patients to get to know staff. Patients can learn about a staff member by watching them with others and watching staff deliver active care to other patients

'You see people who are now more confident, at doing various things' (Jerry, Patient)

Staff can get to know patients by;

'Being themselves, and introducing themselves, trying to gain confidence with the patients, and obviously, the patient's got to gain confidence in them, cause they are putting needles in our arms!' (Emma, Patient)

'The same every time, like have you got family, are you home alone? You know cause at the beginning you are trying to find out a bit about them, you very quickly build up a picture of the person, even after the first session. And you tend to remember it for next time' (Charlene, Registered Nurse)

Lack of Familiarity

When patients are new to dialysis, or new in the unit, or being looked after by staff they do not know, there are concerns over the lack of familiarity of the staff.

'When they first brought me through here I hated it because I wasn't sure of the staff' (Betty, Patient)

As patients do not know the staff, it takes a while to become familiar with them and learn about their likes or dislikes.

'You need time to suss them out to figure out if they're going to be talkative and if they want to have a laugh or a joke with you, and it can take you a wee while to figure that out' (Sandra, Patient)

Patients place a high value on familiarity, so being looked after by someone who they do not know changes how the patients will make use of the staff in the unit.

'I'll wait till I see someone that I've known' (Martha, Patient)

'When they first brought me through here I hated it because I wasn't sure of the staff' (Betty, Patient)

'You see staff coming in, and you think what's their experience, and even the other night I said that, one of the members of staff, he was fairly new, I didn't know him, and I thought, you are a bit wary letting people near your fistula' (Martha, Patient)

'It can be disturbing, cause you are used to certain people there....but for patients it's nice to see the same staff' (Rita, Patient)

'I was reticent to disturb the nurses when they were sitting at the desk doing their notes and stuff, to sit and ask for stuff, so I would sit maybe not feeling well, and need something and not say anything (Donald, Patient)

This suggests that when staff are unfamiliar, it can have an impact on the care given, as patients do not ask or initiate with the nurses that there is a problem or requirement to do anything.

Some patients do not think that there is an impact on them when they are being cared for by someone who is not as familiar to them.

'It doesn't matter what nurse it is, I'll ask her, it doesn't matter to me, you are all there to help, that's what you are there for' (Martha, Patient)

Being Interested

The staff and patients both remarked about taking an interest in each other and how this was an important part of the dialysis experience.

'Just speaking to these people, all be that as part of their initiation, discontinuation, midway check, looking at this, discussing their fistula, discussing a future procedure, something that has changed with them at home, but still looking interested, and that's the key, and continuing to take interest' (Darcy, Registered Nurse)

'Today a new patient came in, never met her, but I asked how are you getting on, this your first time here? Maybe just to say to them, how do you find the ward, and is she is a young lass or an older woman-how's the weekend? Or do you have family that have been in to see you? Stuff like that, it's just, and you get to know them a little bit, and make them feel at ease, instead it's just all about meeting that person' (Billie, Support Worker)

These quotes highlight that for registered nurses and clinical support workers, taking an interest in the patients was a focus of their time and care.

Being interested in the patients and their lives outside dialysis was something that staff identified as something that was important.

'Getting involved in the discussions about family, about events, something as simple about what did you do on Saturday night? I think a lot of patients really like that' (Charlie, Registered Nurse)

This section from the researcher's fieldnotes shows an example of a member of staff showing interest in a patient.

21:45 (Observation 10)

Julia (nurse) is just finishing taping Robbie's needles in place, 'What are you doing over the summer' she asks him.

*****I find out that Robbie is a student and finishing his course for the summer months soon. The nurse is showing her interest in his life outside dialysis and also that she has an awareness of his personal life and relationship between themselves prior to this encounter/ conversation.***

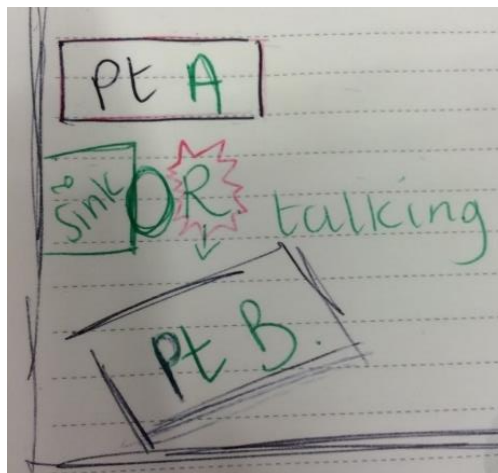
Patients also stated that the nurse taking an interest in them made them feel like a person, not just a patient. Understanding them, not just from a medical point of view, helped them and this was also reciprocal.

'The nurse's personality, knowing your medical history and knowing you, not just medically but family history, if a nurse shows an interest in your private life without intrusion, you feel interested and it works both ways' (Edward, Patient)

Patients took an active interest in knowing about the staff who work in the unit and that care for them. They did this by asking questions and having conversations with the staff.

'I want to know about the nurses, it comes out automatically, chatting away and If you say oh right I'm going away for the weekend somewhere, the nurses say oh I've been there before, and that triggers and you get also triggers, oh you have a sister and things like that' (Edward, Patient)

In the fieldnotes, during an observation session, one nurse was busy preparing for putting on a patient, when another patient begins to ask questions and take an interest in her pregnancy, despite her being about to commence another task with another patient.



Rhys (Patient B) just asked staff nurse Elaine about how her pregnancy is going, 'when's the next scan', you'll be finishing up soon then' Elaine is washing her hands in the sink beside this patient, but she didn't put him on, she is just passing by between putting on patients and washing hands. She is about to put on the patient next to him, Sarah (Patient A)'

This interest from patients to staff, despite if they are actively caring for them or not, occurred throughout the observations, and was a way of maintaining a connection during the session with staff.

The opposite of being interested is not being interested. One patient spoke of a situation where a staff member did not make her experience of dialysis particularly enjoyable, where they felt the member of staff was not interested in them.

'Some of them, some of them can be really cold, really cold, they dinny want to have eye contact with you, cause if they have eye contact with you, then they think they're obliged to talk to you- which they're not' (Betty, Patient)

Staff not being interested in the patients was also reflected in a situation for Betty, where one member of staff was not interested and spoke quite abruptly to her when putting her on dialysis.

'But I had to tell them you're awfie cold, you're really cold and it's no nice being on the receiving end...hold that, hold that, will you just hold it....Nae other nurse has certainly not spoke to me like that but you better get your act together, cause it's no right, what you're doing, you've no got any duty of care to the patient at all' and I have them a lot' (Betty, Patient)

This idea that the staff might not as interested in patients as they are in the machines or the more technical skills was also viewed as a negative from another patient.

'Some (staff) are more technically orientated than the care of the patient' (Rita, Patient)

The clinical skills are not always viewed as the most important aspect of the haemodialysis experience.

'Clinical confidence and this kind of emotional support that you can give to people is different, and I don't think necessarily it has to be someone with good clinical skills that is the one' (Marty, Registered Nurse)

This quote highlights the importance of being interested, rather than having high technical clinical skills.

Patients identified that not all staff would share about themselves with the patients.

'Some people (staff) share quite a bit. And some people share nothing' (Jerry, Patient)

Rapport

Having a rapport with the staff allowed the patients to feel happy and confident in their treatment and experience.

'We are coming in for important treatment and we come 3 days a week, 4 hours on the machine at a time, you want to be happy with the people around you, want to have confidence in the, you don't want to be saying oh so and so is in here' (Rita, Patient)

This fieldnote illustrates the rapport and relationship between a nurse and a patient during the commencement of dialysis.

Observation Session 2

The nurse is putting the patient on to dialysis, connect them to the machine, 'right, 12 o'clock, shallow or deep?' she asks, shallow he responds, the needle appears to just pop in and the patient then holds the tail of the needle while the nurse tapes, she has not asked him to do this, and does not appear to have signalled him to hold it. The nurses picks up the second needle, 'up to much yesterday?' the patient says he has been going to the gym. He has been going with someone 'going with someone helps motivation', 'well they are back to work now' – 'you'll need to get some good tunes' she says and laughs! And he smiles back, the second needle is in and taped up.

Silence now between them as the machine is connected and HD begins.

One way of building or developing rapport between staff and patients was through observation of the way staff care for other patients and what they do in view of the patients.

A patient described having a lack of rapport with a staff member because they had witnessed them not participating in the dialysis activities.

'I do notice her standing about a lot. When everybody else is doing something, and she's the only one out of the ones who wear the light blue that is like that, the rest of them they do run about and do for you.... She's no wanting to be here, that's what I think anyway'
(Betty, Patient)

There was a value judgement made by this patient on standing about as not being a positive or caring thing to do. This impacted on the relationship that the patient had with this staff member as they felt they did not value them.

'You might not think you are having an impression on patient, but you obviously are' (Angie, Registered Nurse)

Staff mentioned rapport as an important aspect of being able to care for a patient and requires to be built and developed.

'To get the rapport with the patient to feel they can trust you with whatever they are telling you that you're going to be giving them the best possible care' (Angie, Registered Nurse)

Sometimes it is easier to develop rapport with some of the patients,

'With some patients, no matter who you are sometimes you just hit up a rapport almost instantly which makes things easier' (Jo, Support Worker)

The development of rapport with the staff helps patients know their different personalities and then patients can adapt to this when they are being cared for by them.

'It's a voyage of discovery for everybody, so you start to get to know people's personalities, who you can joke with, who you shouldn't joke with' (Jerry, Patient)

Without this rapport, staff felt that it can be harder to care for patients and have an impact on the care or treatment being delivered.

'It can be a handicap if you don't have a rapport with the patient'
(Angie, Registered Nurse)

'You do have a better rapport with your patients, and I think if you've not got that, the patients are less receptive towards you, and they won't comply, they won't listen to you when you say you have to comply with their fluid' (Charlie, Registered Nurse)

There was also a difference between the roles when it came to rapport, where some patients felt that they had a different relationship with the support workers than they did with the registered nurses.

'You can still ask questions, but you don't have the same rapport with them (the support workers)' (Rita, Patient)

This lack of rapport is important. Rapport is something which patients value from staff, and the patients acknowledge a different relationship with the support workers than the registered nurses.

Some patients commented on negative aspects, where rapport was difficult to achieve, or was damaged due to staff behaviour.

'There is one member of the team, who inadvertently became more chatty but not in a positive way' (Jerry, Patient)

Whilst patients want the staff to chat to them, they have been in situations where this conversation did not have a positive outcome.

Trust

Trust was something which both groups identified as important in the connection or relationship between them.

For a relationship to develop between the staff member and the patient, some trust needs to have been established between them.

Trust develops because the staff are nice to the patients.

'The new nurses who are starting, they are usually quite pleasant, nice to get along with so you don't feel too strange with them' (Emma, Patient)

The importance for patients to trust the staff as being able to do the job and carry out the treatment was important.

'When the patients viewed me as competent that's when the relationship started to build, They are kind of sussing you out in a way' (Jo, Support Worker)

This conveys the idea of clinical trust needing to be established before patients could develop a relationship with the staff.

Patients do not trust staff automatically, they want to know who they are and their level of experience, in order to establish trust.

'It's very important because you have to have confidence in people, - your life is in their hands basically, you do need to have confidence in them, know that they know what they are doing, what they are doing is right' (Sandra, Patient)

The trusting of staff, especially in relation to the fistula, was something identified by the patients.

'Good to have confidence in other people coming in, and being able to do your fistula, cause you get quite protective of it, it is our lifeline, and eh, I'm a bit wary of people touching it, if you don't have confidence in them' (Rita, Patient)

Donald trusts all the staff, but is more likely to ask questions and engage with the staff he knows, whereas when being cared for by staff he does not know as well, he will go along with what they say.

'If someone I didn't know said oh we are putting you on HDF¹³ I'd be like okay then. But if it was someone I knew, I'd say why, what does that mean, you know' (Donald, Patient)

He had trust in the staff because of the job they did and the position and knowledge they had.

Emma identified that she knew that certain things happened because she trusted the staff to do things e.g. medications.

'I know I have had the medication that I'm meant to' (Emma, Patient)

The importance of trust is acknowledged by the staff. If the patients trust the staff, then they are able to care for them and provide education and support.

'They are relying on us a lot, cause they are coming in and we are keeping their life going, we are doing their treatment, the thing that

¹³ HDF is haemodiafiltration and a type of dialysis.

keeps them alive building up a trust with them, and hoping they will trust you enough, that if there is anything going on they will talk to you about it' (Dani, Registered Nurse)

Staff felt that trust developed through caring for the patients and being part of their dialysis team.

'The trust, it was because I was always there' (Dani, Registered Nurse)

6.5.1.1.1 Lack of Trust

If patients don't trust the staff, particularly in relation to their clinical skills, then patients can feel uncomfortable.

'But you tend to trust the people that are doing it, and that they know what they are doing and unfortunately that might not always be the case, they might be more gung ho than they necessarily should be' (Martha, Patient)

The patients know about certain aspects of care as they understand their treatment.

'You've got to watch some of them' (Sandra, Patient)

One patient explained that she had witnessed a staff member not washing his hands and not putting on an apron. She then told him to go back and wash his hands and get clean gloves.

6.5.2 Group Relationships – 'It's like a little club'

Within the dialysis unit, there is a sense of group or community amongst the patients, staff and also both groups together as one community.

'We are united by a common factor, we all have failed kidneys' (Jerry, Patient)

The patients who come to the hospital rely on the other patients as a group, every session and use each other for both distraction and support.

'The other patients seem to know, they would probably tell you! The patients do talk amongst themselves!' (Donald, Patient)

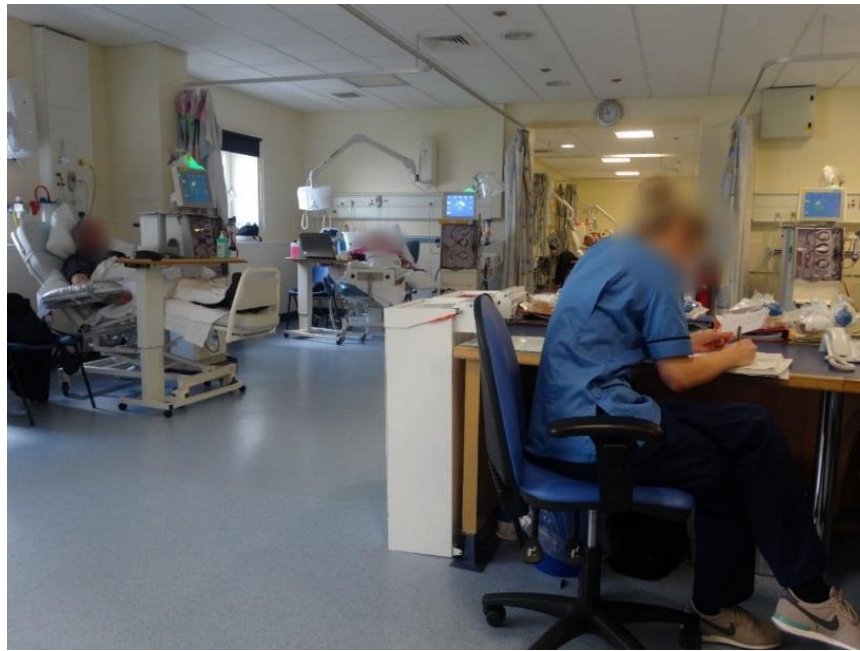


Figure 63: Members of one dialysis patient group in their room

One patient identified the group she dialysed with, a relatively new group as she had moved rooms recently. She knew a bit about who was who in the room, what usually happened and how much they engaged with her.

‘David can be really unwell, there’s a new girl in there I don’t know her name, and eh, I don’t know anything about her, and Ian. Ian doesn’t speak, Keith will say hello and cheerio and that’s it, eh the guy next to me, Paul, and so does the other guy so it’s only hello and cheerio’ (Betty, Patient)

Despite this lack of knowing names and minimal chat, she was still interested in them and the group as a whole.

Groups as Support

Patients use the other patients who are on dialysis as a source of information about their treatment and value their opinions and knowledge.

‘You are able to help some patients when we talk in the waiting room, or on the transport backwards and forwards’ (Rita, Patient)

Staff can instigate patients looking after and supporting other patients, when they are new and uncertain of procedures.

'If you can engage other patients to help other patients, it helps them'
(Angie, Registered Nurse)

The patients, whilst not being formally introduced to each other, do get to know each other through attending for treatment.

'They weren't introduced, that takes a little while, you don't say much in the beginning, but then sometimes people are only there for a day, so you don't know whether they are going to stick around or but after they have been a few times you get talking to them' (Donald, Patient)

The registered staff acknowledged the value of patients being able to ask each other questions, rather than asking staff for answers of information.

'It's better that they can ask another dialysis patient' (Angie, Registered Nurse).

This facilitates a relationship to potentially develop between the patients.

Patients also support each other in different ways; two patients regularly go to the shop together. They get dropped off by their transport, and will head to the shop in the hospital before they come into the unit for treatment.

There were numerous occasions where hospital blankets were fetched by patients for other patients. Other examples of patients helping each other included bringing the, daily papers, crisps, or cups of water and ice, sometimes without anyone asking.

'Michelle is a patient, she brings in a packet of crisps and the mornings paper for Jim every shift, and then goes and gets cups of water for all the patients who are already on before she then goes to her chair for starting treatment.'

'Hello everyone' she says as she enters the room, and heads to the only vacant seat, she is usually the last one into the room as she does the shortest time on dialysis'

This was part of Michelle's daily dialysis routine, making sure that the other patients in her room had the things they wanted. Jim was in a wheelchair so couldn't get the paper in the morning without assistance, so Michelle would bring it in for him every dialysis day.

There were various examples of the patients sharing their things, particularly magazines or papers, but there was the sharing of ‘goodies’ like biscuits or small cakes between patients, but these were usually passed round by the staff at the patient’s request.

‘Can you pass this magazine to Nancy for me, I’ve finished with it, the nurse who is beside the patient obliges and says no problem, and walks over to the patient for whom the magazine is now for, thanks she shouts over the room’

The patient is off the machine now, and the support worker is tidying up the space, and putting things in the bin- ‘can you pass that paper over to Bill, thanks’

Talking amongst the group

Patients did talk to each other at various points throughout their time in dialysis and whilst on the machine. Patients talked to each other about a variety of subjects. They would arrive in the room and would acknowledge each other’s presence, and also presence of the staff.

‘We do have a natter, and say hi and everything’ (Martha, Patient)

Patients did talk to each other about dialysis and topics unrelated to dialysis. They followed up on conversations from the last session, asking about family or the social plans they had shared with each other.

‘Two patients are talking to each other (they are on dialysis, with needles in their arms) discussing Scottish history and politics. The rest of the patients are doing different things reading and watching TV, but this pair are leaning towards each other on the dialysis chairs and chatting away’

‘We have giggles and laughs and things, which keeps your spirit up’ (Barbara, Patient)

The layout of the room does not always allow for the patients to talk, one felt that being round the edge of the room, sometimes quite a distance apart did cause difficulty in communicating with the other patients;

‘can’t shout across you know what I mean, it’s a bit hard, aside that it’s alright’ (Judy, Patient)

‘After he has stopped bleeding from his fistula needle site, Justin passes by Nikki, on his way to the scales, and asks how she is doing, and how her weekend had been, he was sitting in the furthest corner from her on dialysis, and was on when she arrived – some things you don’t shout over the room’

The twilight or evening shift is regarded as a quieter shift. One patient explained that

‘During the day, there is much more banter, there is more people talking in between’ (Martha, Patient)

The importance of getting on with the patients and staff who are in the unit was also pointed out by patients.

‘It’s about the staff, but it’s about the patients as well, if you dinny get on with them it’s going to make it a long shift’ (Sandra, Patient)

The conversations allow the patients to get to know each other;

‘Some more than others’ (Martha, patient)

Some patients do not want to engage with the other patients very much. When one patient was asked about talking with the other patients, he explained that

‘The only time I talk to them (patients) is in the waiting room. That’s basically it, they never seem to talk about dialysis or that, it’s about what’s happened today or news wise, or something like that’ (Bob, Patient)

Whereas others, like Phil, did not like being away from his group of friends on dialysis when he had been in a room and then required to be isolated in a cubicle for clinical reasons.

‘All my mates are in there (room), stuck in here (cubicle) you’ve got nobody’ (Phil, Patient)

He did not enjoy being moved into the cubicle, and got enjoyment from being in a room with his regular dialysis group of ‘mates’.

Not engaging with the group

Some patients do not engage as much as others in the community group. Patients know that they spend their time on dialysis differently.

‘People just come in at night and sleep’ (Martha, Patient)

‘Others may just want to come in and have their dialysis, and just get through it’ (Martha, Patient)



Figure 64: One patient watching television

Some patients did not engage with the other patients during treatment. Figure 64 shows one patient who did not communicate with anyone once they were on the machine, and then did not speak again until they were coming off dialysis. When they were given tea and toast, the staff just placed it on the table and the patient did not respond. The patient had headphones on whilst watching the television.

Despite this, the patients try to involve the other patients who are in the room in their chats and discussions.

Emma, a patient who had been attending for dialysis for a few years, remembered when there were group activities in each of the rooms, which allowed for everyone to be involved and have fun during the dialysis treatments.

'Involving other people, who dinny read or dinny sleep, it's quite a long time for them to lie with nothing to do, and when we used to have wee quizzes and that, it became quite funny, especially with the answers that were given' (Emma, Patient)

The sharing of experiences and knowing someone else who is going through a similar situation was of benefit to the patients.

'It's helpful having other patients, people going through the same thing as you, being able to talk, have a joke and a laugh' (Rita, Patient)

This highlights the support and camaraderie between the patients when having difficult times and also that the companionship makes it a more enjoyable experience.

The patients care and look out for each other when they see others in distress or are concerned. One patient said that they would point out to staff if they were worried, or if 'somebody who has bad cramp is hanging of the side of the bed, I think they are in trouble', they would notify staff. This was reciprocal, as other patients had done the same for them.

'I think this teaches you to be more caring, I'd like to think I'm a caring person anyway other people to think about as well as yourself' (Rita, Patient)

The patients do think about each other and are affected by any that leave; whether that be for a transplant, are unwell so missing and receiving dialysis on the ward or in the case of them passing away.

'Cause you know some patients are going to get transplants, and some sadly pass away, and these are the things we have to deal with, happy for the ones who get transplants, obviously upsetting when someone passes away, and that can be quite a sad day, and you do find the room is more sombre that day, with everyone thinking who's next basically' (Emma, Patient)

The community is constantly changing, as patients leave, due to transplants or passing away. The patients who remain do feel a change in the atmosphere, but they then get used to it.

'Each time somebody new comes in you get used to it' (Emma, Patient)

The patients also develop a bond with the room and an attachment to being in a particular space for their treatment.

'I've been in that room since I moved to the new hospital, I would hate not being in that room' (Emma, Patient)

Groups being different

When patients move shift or room, or they are in a group that they do not know as well, patients can feel awkward and uncomfortable because they do not know the patients or staff in the room.

'That's awkward, cause you don't, cause unless you know someone who is in that room, then you are sitting and you're not really talking to anybody, whereas we shout at each other, and have a laugh and a joke and that, erm, but not all the rooms are like ours!' (Sandra, Patient)

The patients in that room may not always talk to them, so time does not pass as quickly.

'Whereas when you're sitting, and you're just sitting and looking, and everybody's just sitting looking at you, and you're thinking hurry up, and everything, you're clock watching basically, aye, it can be awkward. Even just going onto a different shift can be awkward' (Sandra, Patient)

The rooms do have different atmospheres or cultures, dependent on the patients that are in it and what they do during dialysis. One patient described his room and patient group as being a quieter group than the other patients in the other rooms.

Observation 2:

*****There is silence in the room, I can hear patients and staff talking together next door at a low grumble but in this room no one is talking, the patients are reading or sleeping or playing on their computers, but next door appears to be in a full blown discussion***

This fieldnote demonstrates the differences between the rooms and groups, with one group chatting and the other room being quieter, with no chatting between them.

Being in a different group has an impact on how the patients feel when they come in for treatment.

‘But the people that I’m in the room with on twilight, I wonder if they think I’m like an interloper! Like what are you doing in here! You do feel it, you do, if you see someone different, you are like who’s that! What you doing on my shift, this isn’t your shift! (Donald, Patient)



Figure 65: Patients chatting together whilst on dialysis

Nursing Staff as a group relationship

The staff, both registered nurses and support workers, were not often in the room as a lone member of staff. Due to the working practices in the unit, there were always two members of staff allocated to work and care for the patients in a room; usually

both of these were registered nursing staff, and there was often a support worker to supplement this. Depending on other factors, for example if the nurse in charge of the shift was an extra member of staff and not counted within the regular room staffing required levels, this could add another staff member into the room to be involved in care. When both shifts of staff were on in the cross over period from 12.30pm-8pm, there could be up to five or six staff just allocated to the room and those seven or eight patients which allowed a high staff to patient ratio at this point in the day.

Due to this constant staff presence and as they were usually not alone, this allowed for staff to form relationships, particularly as a group who were working on shift together. Staff would be sitting or standing round the desk or in the middle of the room talking together.



Figure 66: Staff around the nurses' desk

Staff were regularly seen chatting to each other, usually round the nurses' desk in each room (Figure 66). The room allocated to the staff for the day was normally the room they described as 'my room'. Staff had a particular room allocated to them as a named nurse, which meant they usually would be allocated to work in this room with the same patient group.

Staff also had fun in the rooms together. One particular situation occurred during an observation session when a support worker was looking for a patient folder, and could not find it (Figure 67).

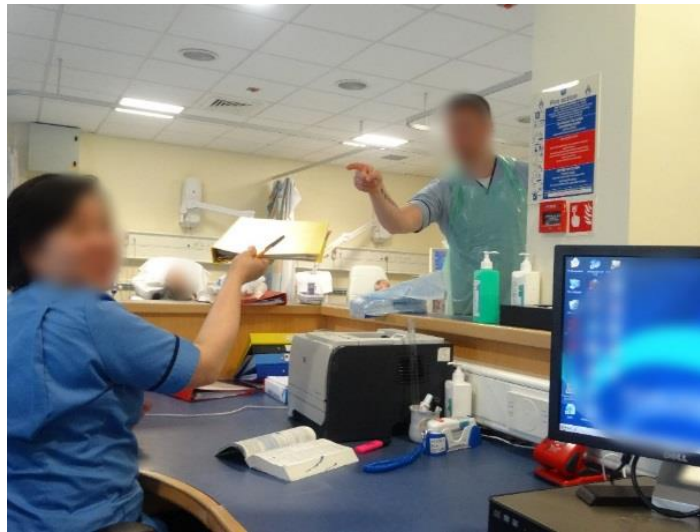


Figure 67: Staff laughing with each other

6.5.3 Boundaries

There are some things which limit or impact the relationships, particularly between staff and patients.

First Impressions

A patient's first impression of their dialysis experience or care has an effect on dialysis and their ongoing impressions.

'Until you are on it you don't know what it will be like, and how you will feel about it, I think the first nurse that put me on was very matter of fact, I think, didn't appreciate it was my first time, and they were very good at cannulating and things' (Donald, Patient)

Professionalism as a boundary to relationships

There is a boundary to the relationship between the staff and patients. Staff are aware of maintaining that professional line between them and the patients.

'It's perfectly acceptable to discuss so much, but there is a line where it stops sort of thing' (Charlie, Registered Nurse)

'They know very little about me, they probably know where I live and that I have a dog and a husband, everything else is kept under wraps, there is no need to know that, I know a lot about them, but with that exchange that works pretty well' (Darcy, Registered Nurse)

Staff also do not want to cross the line and delve into patients' private or personal lives if it is not wanted, so they try to keep a professional distance between them whilst having a relationship.

'Tend to try and talk to patients to a certain degree, where I am not impinging on their personal life and that kind of thing' (Jo, Support Worker)

'You do have to build up a rapport with the people you see all the time, you can't just have a line - I know there are certain things you can't cross, you just get to know them' (Edward, Patient)

Here, Edward acknowledges that there is a boundary in the relationship, but that staff do not just have a set 'line' or way to communicate, that they treat him as an individual.

'Your space when they are putting me on, to get to know me, talk to them, they can talk to you, you get to know them a bit about their life, get to know about your life, and it makes you, more for when you are having someone strange, you know something about them, you know if they have problems in their life, you can treat them appropriately everybody has things happen in their life, everybody has things happen in their life, you can't always expect them to be singing and smiling' (Emma, Patient)

'I feel like we are part of their family' (Angie, Registered Nurse)

'I was really upset and I was crying. And one of the Nursing staff came over, and she said are you okay? Noticed I was upset, but I was lying on my back and she was across the room, so it was quite difficult to notice but she did, I just said no I'm fine, she left it at that. She didn't force the issue, she didn't ask me why I was upset, so they knew as well not to cross the line, to give me my space' (Martha, Patient)

Clinical Experience as a boundary to relationships

Lack of clinical experience from staff affects the relationship. The patients and staff both highlighted that not having experience or confidence in the clinical area did

impact on their ability to offer support and advice or affected who would be targeted for information.

'Something I wasn't sure about, I would probably want to ask somebody who knew more about it rather than someone that didn't know as much, just started in renal, its new to them as well so they aren't going to know as much as someone who has been here longer'
(Emma, Patient)

'If they do your cannulation really straightforwardly, you think I hope I get them again, if you have someone who faffs around a bit and doesn't quite get it, you think I hope I don't get them again!'
(Donald, Patient)

Negative experiences can affect patients and their thoughts of new or unknown staff.

'At the beginning, my fistula blew, it was someone I hadn't had before, and I was thinking I hope I don't get them again, even though it wasn't their fault, nothing to do with them, still quite new to it, but I hadn't had them before, I'd had the same people, at the beginning, But then this new person came along, and I haven't had them again, and I think if they came along again I think I'd still be quite nervous of them doing my fistula, even though my fistula is quite stable and settled, easy to cannulate, I'd still be (Donald, Patient)

'Some of them who are really set in their ways and have been there for a long time and I suppose stay away from the newer ones to start with (Dani, Registered Nurse)

This quote highlights that the staff's focus when learning is on the older, more established patients who have different needs, rather than the new patients who are learning about dialysis and in a different position.

Patients also consider the experience level of staff, and know the differences in their knowledge and ability.

'I know that some of the more experienced ones do have more insight into some of the things' (Emma, Patient)

Job as a boundary to relationships

Clinical support workers discussed situations where they found it difficult to develop a relationship with the patients.

Being young and not a registered nurse affected the way patients saw the three support workers who were interviewed in this research.

'It does hurt a wee bit sometimes' (Jo, Support Worker)

'Sometimes I think they are looking at me thinking what do you know, you are half my age' (Billie, Support Worker)

'Aye I've had the brush off- it doesn't really bother me' (Lewis, Support Worker)

These comments from support workers highlighted that sometimes they were aware of being treated differently by patients; this sometimes had an impact on the relationships and care delivered.

6.5.4 Maintaining a connection

Patients and staff, when walking past or doing checks, would be acknowledged by the patients using vocal responses like 'thank you' and staff asking questions like 'okay?'. These didn't always get a verbal reply, but an acknowledgement through a nod or a smile.

One of the rooms had a thoroughfare of patients and staff passing through, due to its location and it linking to the other rooms and the waiting area and scales. Due to this, both this staff and patients would walk through before, during and after dialysis treatments, which meant they would pass a lot of the patients or staff in this room. Patients would be acknowledged as both staff and patients walked past them, and some patients even gave the staff in this room their weights to pass through to the other staff in their room. This was done for both efficiency and also sometimes allowed a conversation between the staff in this room and the patient, who they had not been directly looking after. Patients would ask each other as they passed how they had been or when they were off and some even stopped to talk more about football or someone else in the unit who maybe was not very well.

Due to the nature of haemodialysis, with patients requiring to attend 3-4 times a week for treatment, the patients know that the staff can know them quite well and their likes and dislikes due to the fact they are seeing them so regularly.

'Obviously they know the people you are closest to, cause they are with you that often' (Emma, Patient)

A patient's attendance and the staff being there during treatment in the unit allows for the maintenance of the relationships.

Due to the shifts of the staff, patients can spend time with some staff members and then not see them for a while. This has an impact on maintain a connection or relationship with them.

'You can come in here, and you know yourself, you might have the same nurse on the trot for three nights, then you might not see her for a fortnight, know what I mean, always seeing different faces' (Bob, Patient)

Staff also found it hard to establish a relationship at times, when some patients are not always as willing to give information about themselves as other patients.

'It's hard you have to tease things out of them' (Marty, Registered Nurse)

15:20

Yvonne comes into room 4, she is just back from maternity leave, today she is working in room 3 but she has come into room 4 and sits down beside Liz (a patient who has been receiving haemodialysis for a few years) on the plastic chair to Liz's right hand side, the dialysis machine is on the patient's left, same as her fistula arm.

15:45

Yvonne is still with Liz, Yvonne has been sharing about her new daughter Jean who is now almost a year old, and how Liz has been doing over the last few months- Despite not seeing each other for at least a year- evidence of their existing relationship from before Yvonne's maternity leave.

This fieldnote illustrates the connection between a registered nurse and patient. The nurse spends time with the patient to tell her about her new baby and how things

have been going. The patient also shares what has been occurring in her life since they last saw each other.

Another way that patients maintained relationships with those around them was by bringing in sweets or chocolates. Patients would either present them to the staff when they arrived prior to starting dialysis, or when they were on the machine would give them to staff and ask them to pass round the patients or to put on the desk for everyone (see Figure 68).



Figure 68: Chocolates and sweets brought in by patients

'Because we have difficulty communicating with them then we don't prolong the agony either for them because they also become frustrated because they can't either they don't understand us so they can't respond and we don't understand them so' (Lee, Registered Nurse)

One nurse identified that by being there for a patient and putting them on for their first few sessions had an impact on the relationship they made with the patient.

'The first few times I was always there in the room, and put him on, so got to know them quite early on in their starting dialysis, so I think it was just, that, erm, I guess we just got a bond, a patient nurse bond

to start with cause I was always there the first few times he was there...' (Dani, Registered Nurse)

Some patients are not interested in developing a relationship with the staff.

'You've got harder patients too, they don't really want to build up a relationship, they're there purely just to have dialysis and go home and that's it, they've got family, they've got people to talk to, they don't need anybody else' (Billie, Support Worker)

6.5.5 Summary of Individual Connections

There is such an importance placed on the relationships in the haemodialysis unit.

The relationships between the staff and patient are key factors in allowing some aspects of care to occur.

The relationship develops over time together as patient and staff member. The staff work hard to maintain the relationships with all the patients that attend the unit, so that they can care for them appropriately.

'we are privileged to look after these people....'.

**** informal questioning with a registered nurse during observation 9**

This feeling of being privileged highlighted the special position of a haemodialysis nurse, where these nurses and clinical support workers can know and be included in a patient's life, due to the longevity of regular attendance in the unit and the connection established between them.

6.6 Summary of Findings Chapter

Despite splitting direct patient care into these disparate elements as themes, the themes overlap and are inter-related and dependent on each other. Patients and staff view care to be composed of three aspects; individualised, safe and comfortable.

Direct patient care is provided in two ways within the haemodialysis unit, either in an active way or a passive way, but both are dependent on the relationships with the staff in the area. The individual connection between the staff and patients, as well as

the connections across the wider patient and staff groups are important within this research as findings. The connection between the nursing staff and the patient is particularly important as it supports the delivery of DPC through these two conceptualised processes of active and passive care.

To illustrate and summarise the key findings from this research and show the links between the different elements a concept model (Figure 69) has been devised.

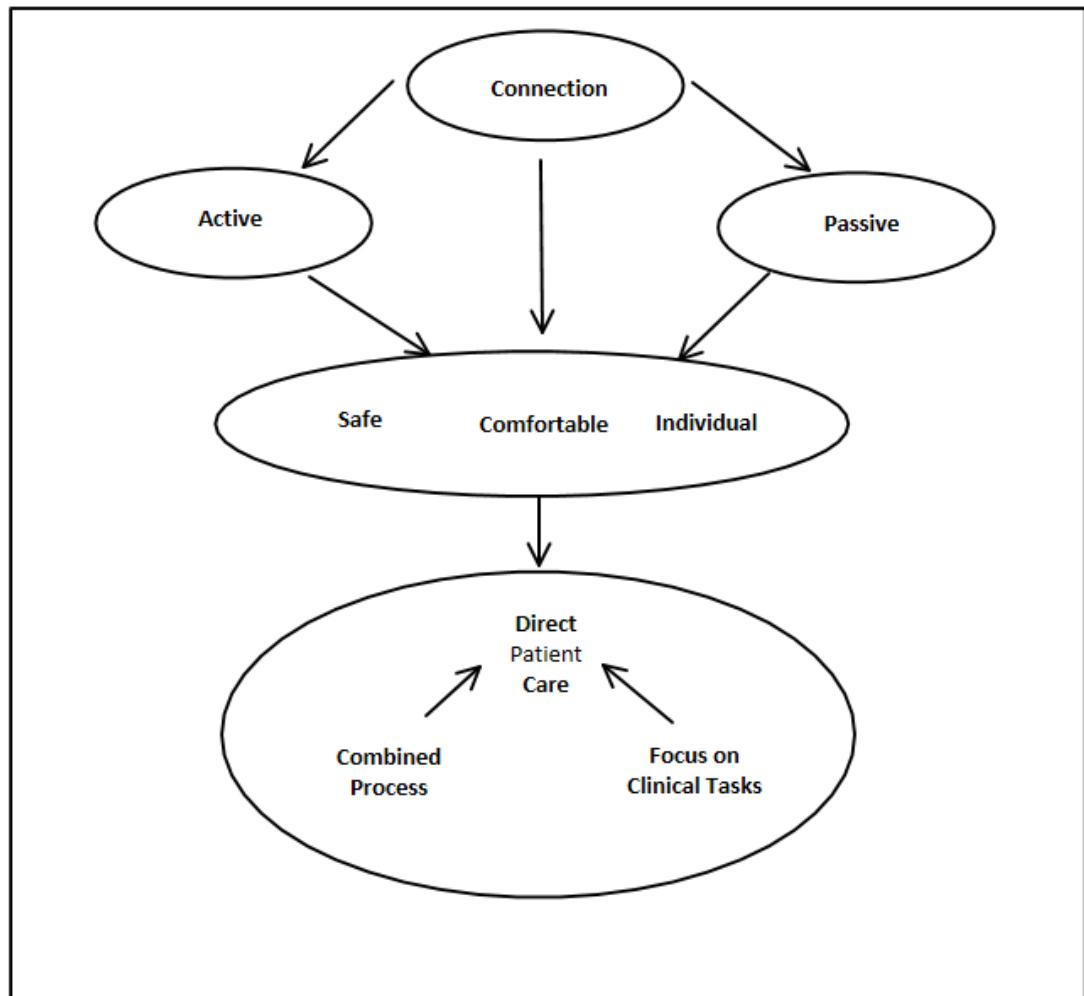


Figure 69: Concept Model of Direct Patient Care in Haemodialysis

This conceptual model covers how the key findings relate to each other when considering direct patient care and will be further discussed in relation to the findings in the discussion chapter and against existing frameworks.

Chapter 7 Discussion

7.1 Introduction

In this study, the concept of ‘direct patient care’ was explored within a haemodialysis unit. The aim of the study was:

To gain an understanding of patient and staff perceptions and experiences of ‘direct patient care’ within one large in-hospital haemodialysis unit.

The specific research objectives were:

- To establish what the patients want and value as ‘direct patient care’ in the haemodialysis unit
- To explore patient perceptions and experiences of ‘direct patient care’ and interactions
- To establish what haemodialysis registered nursing staff view as direct caring activities for haemodialysis patients
- To establish what haemodialysis clinical support workers view as direct caring activities for haemodialysis patients

The original contribution to knowledge in this PhD is through the unique insider focused ethnography conducted within a large haemodialysis unit, which has provided evidence to allow a reconceptualisation of care. This is through the evidence provided from the unique insider perspective. This allowed the dynamics of care to be explored and investigated further alongside some of the underlying subtleties of how care is to be defined. The emergent idea of passive care is an element which is hugely important to both the patient and the nursing staff. It is a combination of the visibility, availability and the connection existing between them, alongside the perceived knowledge or wisdom of the nursing staff as identified by the patient. However, it is also the skill of the nurse to know and understand when the patient needs to communicate or be left alone as well as the technical expertise and knowledge, alongside the knowledge of the patient’s condition and pathophysiology. All of these elements require to be present and are integral to the concept of passive care as described within the findings (Section 6.4.2).

There is also a contribution made from this work into the use of ethnographic research work, and this unique position of an insider researcher within a previously known clinical area.

The previous chapters present the findings from the ethnographic research relating to both the environment and context of the haemodialysis unit where this direct patient care took place, and also the patient and staff's understanding of their experiences of this concept of care. The context of the haemodialysis unit is important, as it provides an understanding of the background and the environment where the patients and nursing staff are involved in direct patient care.

Considered in this discussion are relevant theoretical frameworks, following the process of data analysis are explored in relation to this research and its results. These frameworks are detailed in this chapter to firstly give insight into the frameworks and subsequently referred to within the discussion chapter. The frameworks are presented here, as part of the discussion within the thesis, following the findings. They were not considered prior to data analysis, and were used to interpret the findings once data was collected and analysed.

This discussion chapter will focus on the key findings, which directly relate to the research aim and objectives. It provides an understanding of the perceptions and experiences of patients and nursing staff, relating to the term direct patient care in one particular context; the out-patient haemodialysis unit. These key findings are discussed alongside the published literature in order to contribute to the understanding of the concept of direct patient care.

Within this chapter, the three elements which constitute direct patient care are considered. These values are safe, comfortable and individualised care. The individual connections between the patients and nursing staff within the haemodialysis unit are also discussed, as they relate to the care provided and received. An individual connection is further divided into the key aspects of familiarity, being interested, trust and rapport.

Following this, the two means in which direct patient care are delivered are explored and discussed; these being active care and passive care. Active care is made up of time together and verbal communication and reflects the original definition of care being when a patient is near and being looked after by a member of staff, similar to the original DPC definition. Staff availability and visibility constitutes what has been described in this thesis as passive care, a way in which care is provided or delivered which contradicts the traditional approach of being directly with or doing to a patient.

The final finding discussed in this chapter is that direct patient care is a combination of many aspects and is regarded as the whole of the combined processes of care. The concept model presented at the end of Chapter 6 (Figure 69) is then discussed as a model in which care is delivered in a haemodialysis unit, against the two previously identified frameworks.

7.2 Caring Frameworks

Caring frameworks were considered once the data had been gathered and analysed. As an inductive approach was used, the researcher sought to see what emerged from the data and not to be constrained or have data predetermined by frameworks prior to data collection.

Frameworks were only considered after the main data analysis to illuminate where the research contributed to existing knowledge and informed new knowledge on about caring. Hence the key themes from the analysis were considered in light of relevant caring frameworks.

Several theories and frameworks were considered for their application and explanatory powers against the findings of this research. The two frameworks that were identified to most closely align with the emergent findings were the Fundamentals of Care framework (FoC) by Kitson et al (2010, 2013a, 2013b) and the Patient-centred Practice (PCP) framework (McCormack and McCance 2017), both of which are considered here. These two selected frameworks were then used to aid the understanding of the findings and develop the concepts that emerged from the data.

The Senses framework was also considered and is presented in section 7.2.4, but was not further considered in relation to the analysed results.

These two frameworks were thought to be applicable to the findings due to their focus on patient experience and the wide variety of aspects in which care was considered within these two frameworks. The Fundamentals of Care framework considered the various elements which constitute patient care alongside the relational elements of care between the nurse and the patient (Feo et al 2017a, 2017b). McCormack and McCance in their PCP framework (2017) have five processes of care with person-centred outcomes being the goal of these processes. However, on closer analysis of the frameworks they were not able to explain the findings as initially expected and therefore a new concept map was developed to support the new findings (Figure 69).

7.2.1 Fundamentals of Care Framework

Kitson et al (2010, 2013a,) has attempted to identify the universal aspects of patient care, highlighting 14 core elements (shown in Table 9). Work was conducted reviewing seminal work and documents were reviewed and the core elements of self-care were identified that might require nursing interventions (Kitson et al 2010). The Fundamentals of Care are activities that are required for every person, regardless of their clinical condition or healthcare setting (Feo et al 2017a).

Feo and Kitson (2016) detail the working definition of the Fundamentals of Care, these being

‘essential elements of care, encompassing physical, psychosocial and relational aspects that are required for every patient regardless of their clinical condition or the setting in which they are receiving care’ (Feo and Kitson 2016 p4),

which began following a narrative review of literature (Kitson et al 2010). These aspects of care cover a wide variety of individual needs as Kitson et al (2010) look to ‘amalgamate a set of care activities together’ p433. These activities are considered as significant in ways to reduce harm, optimise recovery and ensure positive patient experiences (Kitson et al 2013a, 2013b, Feo and Kiston 2016). Nurses, and the

wider healthcare team, carry out these tasks or care activities (shown in Table 9) to help and support the self-care of people in aspects of eating, drinking and elimination, amongst others (Feo and Kitson 2016).

Table 9: Fundamentals of Care (Kitson et al 2013a)

Safety, prevention and medication	Comfort (including pain Mx)	Rest & sleep	Communication and education	Elimination	Eating & Drinking	Mobility
Respecting Choice	Expressing sexuality	Dignity	Temperature control	Respiration	Personal cleansing & dressing	Privacy

The Fundamentals of Care Template and Framework (Kitson et al.2013a) established three dimensions. These were establishing the relationship or encounter, assessing and delivering physical, psychosocial and relational fundamental care and delivering these elements in the wider healthcare context of resources and teamwork and highlighted in Figures 70 and 71 (Kitson et al 2014). Kitson argues for a renewed focus on fundamental care, due to evidence of failures (Francis 2013) when attending to people's fundamental care needs, resulting in poor patient safety and quality of care (Feo and Kitson 2016).

Kitson's work has focused on the conceptualising the fundamentals of care which comprise physical, psychosocial and relational aspects of care, such as hygiene, nutrition, dignity, respect, and empathy (Kitson et al 2013a, 2013b). Kitson and others view these fundamentals as undervalued and invisible in the wider healthcare systems.

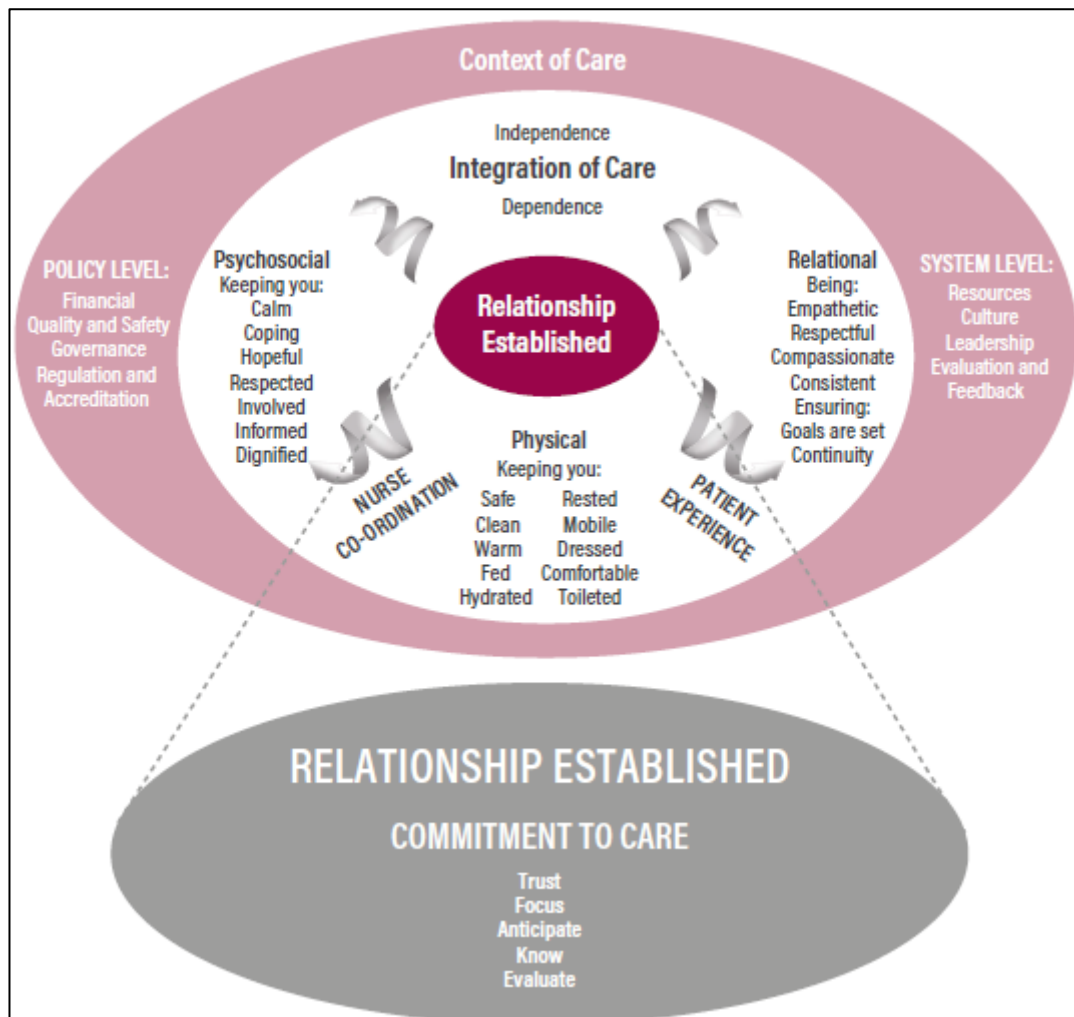


Figure 70: Fundamentals of Care Framework (Feo et al 2017a, 2017b)

The delivery of basic care by nursing staff is highlighted in this framework. Considering the Fundamentals of Care framework against this research was considered important, as it appears to cover a variety of different caring aspects which would be considered as direct patient care in the original definition as ‘time with patients’.

This framework has been tested, demonstrating that different patient groups have different needs and that patients’ experience of care is affected by their relationships with health care professionals (Kitson & Muntlin Athlin 2013, Kitson et al. 2013b).

Central to the framework is the relationship between the patient and the nurse based on a commitment by the nurse to care for the patient or significant others.

Fundamental care needs are one means of providing respectful, dignified patient-

centred care and suggests the importance of a relationship between the healthcare professional and the patient.

In the framework, establishing a positive nurse patient relationship requires five elements (Kitson et al 2013): developing trust with patients, focusing on patients and giving them undivided attention, anticipating the patient's needs, knowing enough about them to act appropriately and evaluating the quality of the relationship (Feo et al 2017b). The five elements highlighted in Table 10 are key in the establishment of a nurse-patient relationship; trust, focus, anticipate, know and evaluate (Feo et al 2017b).

Table 10: Definitions of the five relational elements of the Fundamentals of Care Framework (Feo et al 2017b p57)

Relational elements	Definition
Trust	Developing trust with the patient is an ongoing process; one humiliating experience, for example, being unable to maintain continence because the nurse did not respond to a call bell, can undermine the trust the patient has in the nurse and their belief that the healthcare environment can support their recovery. Nurses require effective communication and interpersonal skills to develop trust in the context of short, intermittent and infrequent care encounters.
Focus	Focusing on the patient and giving them your undivided attention, without being distracted. Engaging with and focusing on the person and considering their self-care needs from their perspective are essential skills
Anticipate	Anticipating the patient's needs, concerns and values, with input from the patient, to minimise stress and proactively meet their needs. Nurses should ask the patient how they can best support

	them, and about possible courses of action that can assist in meeting the patient's goals.
Know	Knowing enough about the patient to act appropriately. This requires effective communication and interpersonal skills to get to know the patient and use this information to inform care decisions, while respecting the patient's need to maintain control, and their privacy and dignity.
Evaluate	Evaluating the quality of the relationship and determining whether it is effective. The patient and the nurse should continuously review progress and give feedback to each other.

The Fundamentals of Care framework provide a model, highlighting what is involved in providing high quality fundamental care; a positive and trusting relationship, meeting patients' fundamental care needs and a context for care delivery which supports these tasks.

The crucial element within this framework is the relationship established between the patient and the nurse or caregiver. These aspects are required to facilitate a positive relationship. The established relationship allows for care to be delivered or from the framework the 'integration of care' where the patients fundamental needs are met (Table 9).

This framework (Feo et al 2017b) also highlights there are occasions when it is difficult and challenging establish a relationship, particularly when a patient is unwilling to enter into this or unable to do so. The framework recommends the involvement of the family so the nurse can establish knowledge of the patient and therefore establish a relationship. They highlight personal resilience as part of the way to care for individuals who are unwilling to establish a relationship.

7.2.2 Person-Centred Practice Framework

Person-centred care is now viewed as the cornerstone of modern and quality healthcare, and patient-centred care is referenced in key government and healthcare policy documents (Pelzang 2010). Person-centred nursing or person centred care is a widely-used idea or concept in nursing and healthcare and therefore is an important framework to consider prior to discussing it in relation to the data presented in this thesis, to provide significant background to the work. Despite the frequent use of the term, there is a lack of constancy and common understanding of the term ‘patient-centred’, leading to multiple definitions across practice, research and policy (Dewing and McCormack 2016).

There are some critics of the person-centred agenda, challenging PCC to be nothing more than a political slogan (Packer 2003) and that it has a too individualistic focus (Nolan 2004). These critiques have added to this concept being widely misunderstood because of the wide use and various misinterpretations due to the term being frequently and widely used.

Person-centeredness is

‘an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant to them in their lives. It is underpinned by values of respect for persons (personhood) individual right to self-determination, mutual respect and understanding’ (McCormack and McCance 2017 p3).

Three main themes have been identified as components of person-centred care from a narrative review and synthesis of literature which identified the common, core elements of person-centred care across health policy, medical, and nursing literature (Kitson et al 2013c). From Kitson et al’s review (2013c), the three main themes were identified as patient participation and involvement, the relationship between the patient and the healthcare professional (regardless of professional group) and the context in which care is delivered. These three core elements transcend professional boundaries, although different professional groups did have various interests and

their priorities varied, which is therefore important to consider here, due to the two types of healthcare professionals.

The Person-centred nursing (PCN) framework was developed by McCormack and McCance (2006, 2010) which focused on person-centred practice and experiences and concepts of caring (McCormack 2003, McCance 2003). McCormack and McCance (2017) have then further developed this original framework into the Person-centred Practice Framework (Figure 72). This evolved framework aims to integrate person-centred care in everyday practice, not only for nurses but to include other healthcare workers.

Some have offered criticism of this work. Edvardsson (2010) has suggested some concerns about the PCN framework and argues that McCormack and colleagues aggregate rather than correlate their different pieces of work. He suggests that they link autonomy plus caring is to be equated with person-centred nursing, and suggests concerns with then using caring inventory to measure this framework (McCance et al 2009).

The framework supports person-centred practice, through different elements or constructs (Figure 72). These are the prerequisites or the attributes of the nurse, the care environment where the care is delivered, the person-centred processes which focus on the activities which deliver care and the expected outcomes or results of effective person-centred practice (McCormack and McCance 2017, 2010, 2006). Within the 2017 framework, the macro context has been added, which suggests the importance of current policy and strategy in the implementation of person-centred practice. The relationship between all these constructs suggests that account must be taken of the prerequisites and the care environment to deliver person-centred outcomes through the care processes (McCormack and McCance 2017, 2010).

The processes within the PCP framework aim to deliver care through a range of activities or components; working with patient's beliefs and values, shared decision-making, engaging authentically, being sympathetically present and providing holistic care. These five processes are described as 'not mutually exclusive but are often interwoven in to the delivery of patient care' (McCormack and McCance 2010 p89).

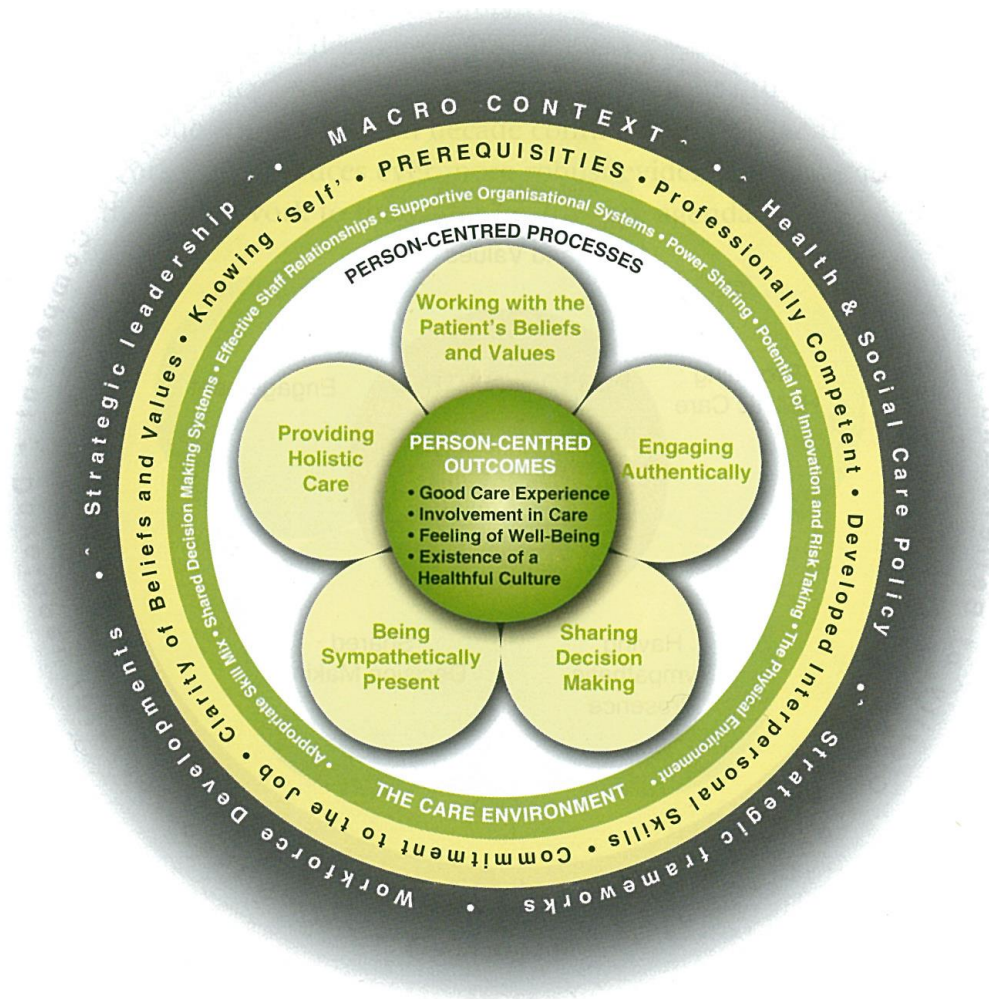


Figure 71: The Person-centred Practice Framework (McCormack and McCance 2017)

These processes are considered here as these research findings focus on the processes or delivery of care in the haemodialysis unit.

Knowing a patient's values and beliefs and supporting and facilitating the decision-making process are both key and identified in these processes. Providing holistic care encompasses the provision of treatment and care which considers the whole person, through physiological, psychological, sociocultural, developmental and spiritual dimensions of a person. Being connected with a patient and others who are important to them, facilitated by their knowledge of them, their beliefs and values and the professional knowledge of the practitioner allows them to engage authentically.

The fifth aspect of these processes within the person-centred practice framework is 'having sympathetic presence'. This term used to describe the way of being with a patient, a way of engaging with a patient and reflecting the relationship between the practitioner and patient. McCormack and McCance (2017) draw on their earlier work to highlight this way of being which is person-centred and also achievable in a practice setting. Sympathetically presence is the engagement by a nurse which recognises the individual, their uniqueness and value. Within this framework, presence is not purely about talking to and spending time with a patient, it is the ability of a nurse to be available to each patient in that moment (McCormack and McCance 2017, 2010).

To be sympathetically present, McCormack and McCance (2017) suggest the practitioner needs to know the patient's beliefs and values. McCormack and McCance (2017, 2010) argue that being sympathetically present is not about sitting with or talking to a patient. Presence can be interpreted in the terms of being attentive or being available. Person-centred practice requires the practitioner to be 'available to each patient in that moment' (McCormack and McCance 2017 p57).

The sympathetic presence element of the framework is an aspect considered alongside the findings presented here and whilst McCormack and McCance argue that presence is interpreted as being attentive or being available however this translates in their exploration of the framework as being engaged in a way that enables sympathetic presence. They also claim that sympathetic presence is the vehicle for delivering the person-centred processes (McCormack and McCance 2010). McCormack and McCance suggest that the notion of PCC being only talking to the patient should be challenged, but they do suggest that being with the patient at a specific moment is imperative to PCC. They suggest that there is an opportunity to be person-centred in each interaction or approach to a patient.

7.2.3 Other frameworks

Senses

When investigating frameworks which would support or fit the findings within this research, the Senses framework (Nolan 1997, Nolan et al 2001, Nolan et al 2002, Nolan et al 2004) was considered. The Senses framework is underpinned by the idea

that all parties involved in caring should experience relationships which promote a sense of six different aspects (shown in Table 11).

This framework does not exclusively focus on the nurse–patient or nurse–carer pair (Dewing 2004), it focuses on nurses being part of a larger social network. The framework also has an audit trail identifying its empirical development (Davies et al 1999, Nolan et al 2004).

Table 11: Senses Framework

Security – to feel safe within relationships	Purpose – to have a personally valuable goal or goals
Belonging – to feel ‘part’ of things	Achievement – to make progress towards a desired goal or goals
Continuity – to experience links and consistency	Significance – to feel that ‘you’ matter.

‘The essence of the Senses Framework is that all participants need to experience these senses if good care is to result. Therefore, it is not just the nurse and patient’ (Nolan et al 2004 p50)

Nolan et al’s (2001, 2002, 2004) vision of relationship-centred care is that good care can only be delivered when the ‘senses’ are experienced by all the groups involved.

This framework was not further considered, as it did not offer a full explanation to the findings presented by this research. This framework was considered but discarded in relation to the findings of this research and its lack of significance as a framework in practice in line with the current findings and the lack of focus on care delivery. There are elements within the framework which do support the findings, but it lacks relevancy on the processes in which this care can be delivered. The two frameworks presented suit the findings of this research more strongly, and have a focus on the care delivery processes and therefore are considered more fully in relation to the findings.

7.2.4 Considering the Frameworks

The Fundamentals of Care framework highlights the importance of the relationship between the nurse and patient. The Patient-centred practice framework highlights the five person-centred processes: working with the patient's beliefs and values, engaging authentically, sharing decision-making, being sympathetically present and providing holistic care.

Both of these frameworks consider the wider context in which healthcare takes place and are therefore useful to consider against ethnographic work which considers the environment, although this research does not consider the full macro context of the environment as both frameworks include this wider element or aspect.

Both of these frameworks are considered in relation to the research findings presented, however on further exploration, they were not as useful as first thought in relation to these findings.

Both of these frameworks are to be considered in relation to the findings which are about to be presented. These two frameworks enable interpretation of the main findings of this research, however there are some areas which do not fit into the frameworks and therefore a new concept model was established (Figure 69).

7.3 Three Elements of Direct Patient Care

Considering the three participant groups in this research, analysis has revealed that direct patient care in the haemodialysis unit is conceptualised to be made up of three key elements: safe, comfortable and individualised care, which as a combination make a shared understanding of this term or concept within the haemodialysis unit.

7.3.1 Individualised Care

The notion of individualised care for patients and staff in this research focused on the premise that all patients are unique and the care required or provided can be dependent on their needs and is adapted to reflect this. Despite the routine, regularity and predictable nature of the processes of care in the haemodialysis unit, striving to ensure the care experienced was felt to be individual to the patient was something that both patient and nursing staff participants reported in this study.

Patients have different needs and the nursing staff recognised that they do provide different things for different patients. The differences in these patients was influenced by the social sphere of the individuals and the time they have been attending for haemodialysis treatment. Other aspects which were highlighted that might have an influence on their well-being and care support needs were home circumstances, recent bereavements or other medical conditions or issues. These all impacted on the potential care they would need, require or receive.

The nursing staff felt they did not make haemodialysis care feel routine or standardised, although some had some well-used, planned questions, they acknowledged that the needs of patients would be and were variable. In particular, the educational needs and subsequent care for each patient was varied and could be constantly changing. The ‘new¹⁴’ haemodialysis patients may require a lot of information around their new treatment regime or in contrast, may not want or need large amounts of education in their first few sessions. This difference is also highlighted by the well-established patients, who may require more care and education around new haemodialysis problems, or other issues. Due to their existing knowledge, they could be less demanding on staff as they required less nursing care, education and information, due to the longevity of their treatment.

Staff, both registered nurses and healthcare support workers, identified that making patients feel like an individual and treating them as a person was important. The staff did not want them to feel like a ‘routine patient’ and wanted them to feel ‘normal’ and not like a patient. For both groups of staff, this was an important aspect of the care that they delivered. Patients had a similar view, where they felt that staff in this dialysis unit treated them as a person and not as a number, or, as one patient participant suggested ‘a piece of meat’.

The provision of individualised care was also achieved in this haemodialysis unit by acknowledging that patients do like or require different approaches related to their dialysis experiences. Things like the side or position of the chair and the machine,

¹⁴ A ‘new’ patient relates to a patient who is new to haemodialysis treatment or to the unit and may require more support due to coping with this new treatment.

having their preferred number of pillows or air cushions already in place, or which physical dialysis spaces patients preferred, due to the TV location, or certain areas of the rooms being more hot, cold or draughty. Remembering or planning for patient preference was important to patients as they felt that staff had considered them in the planning of the room or the day's workload. The routine of the patients and the regular space or attendance assists in knowing the patients and allowing some individual aspects to be identified and planned for by both groups of nursing staff.

In this study, patients felt they were treated as an individual through nurses' actions and interactions. Individualised care is a term commonly used in nursing literature and is an essential concept related to person-centred nursing care. Individualised care focuses on the non-standardised or routineness of nursing care and perceptions of individuality in the care received. Individualised care has been suggested to increase patient satisfaction (Suhonen et al 2012). It is designed to meet the needs and preferences of a particular patient at a particular time and context, acknowledging the patient as an individual and adapting the nursing interventions to that particular patient. Individualised care can result when a nurse knows the patient as a 'unique individual' and tailors the nursing care provided to a patient's experience, behaviours, feelings and perceptions (Radwin and Alster 2002 p62).

The feeling of being treated as an individual and the provision of individualised care in the haemodialysis unit, relating to the patients' needs has been previously identified as an important aspect of nursing care. Other research has suggested that this individual care as a part of nursing was regarded by patients as part of good quality care (Attree 2001) and it was important for a patient to be valued as a person or an individual (Suhonen et al 2008).

Individualised care, specifically through nurse-patient interactions, highlighted in work by Åstedt-Kurki and Haggman-Laitila (1992), was suggested to be important for patients, so that nurses could secure the intimacy and individuality of a patient or client. In this work, there was an expectation that patients would be treated as individuals, with being listened to and the provision of specific or individual information suggesting good nursing care in this research.

Hedgedus (1999) also identified that nurses and patients regarded individual care to be an important part of caring behaviours within their quantitative research conducted in the US. In this piece of research, when testing a scale of nursing caring behaviours, Hedgedus identified that patients or consumers that recognised nurses treating them as individuals was the most caring behaviour that they could experience. As this research was quantitative, no significant detail can be drawn to individualised care, however the results echo the detailed findings presented here, where individualised care was a distinct aspect of the nursing care provided by staff and was wanted by the patients in the haemodialysis unit context.

7.3.2 Being Comfortable

To be comfortable was an aspect of direct patient care that patients described and was provided in different ways in the haemodialysis unit. It was a crucially important aspect to the care provided in this area. Being comfortable as a theme was made up of two particular aspects; the physical comfort from physical equipment and the dialysis environment and inter-relational comfort which reflected the people, their roles and the relationships which were experienced.

Physical comfort was expressed as an important part of the dialysis experience. This was achieved through the use of preferred chairs, cushions or pillows and the provision of things patients need or want when receiving their treatment, like cups of water or blankets.

Inter-relational comfort was comfort provided or felt through the other people in the room, both groups of nursing staff and also other patients. Staff attitude facilitated feeling comfortable in the unit and knowing the staff allowed this feeling of comfort for patients when on haemodialysis. The importance of staff attitude echoes previous work by Chenitz et al (2014), who established in their research that haemodialysis patients feel that nurses and technicians make the patients feel comfortable through having nice personalities and being attentive.

The findings in this current study also contribute to the understanding and importance of feeling comfortable in hospital. Building on empirical work in this area by Åstedt-Kurki and Haggman-Laitila (1992) who suggested that a sign of good

Perceptions and Experiences of Direct Patient Care nursing, and something which is important to patients, was feeling comfortable, particularly when relating to interactions between nurses and patients.

7.3.3 Safe

Being safe or feeling safe was an aspect of direct patient care identified, described and experienced within the haemodialysis unit. There were different aspects within this particular theme, identifying the importance of the staff and their position in the room, an aspect of safe working practices within the area.

Both groups of nursing staff and patients suggested that ‘keeping an eye’, particularly when patients are on dialysis, was important. The patients also kept eyes on each other, along with the staff who were present. Having people, both nursing staff and patients, watching the patients on haemodialysis allowed this feeling of being safe when in the unit and receiving treatment.

The practices and procedures in the unit also added to the feeling of being safe. The knowledge and understanding from the patient and staff groups of the procedures can allow everyone to feel safe. The patients knew the checking procedures and expected staff to check the machines at certain points, which enabled them to feel safe. It is a combination of the practice of it happening and the knowledge that it will happen.

Literature exploring safety in the haemodialysis unit has supported this particular finding. Empirical work by Lovink et al (2015) requires comparison with the research findings presented here. Lovink et al (2015) similarly established that the haemodialysis nurse has a role in the patient’s feelings of safety, although it does not acknowledge the role of the support worker in this work. This work had similar results that patients felt safer in the presence of other patients rather than in a room of their own. Lovink et al (2015) also has suggested that the ‘presence’ of the nurse made the patients feel safe, through their close proximity and the ability to call them through a monitor or alarm system. Although within the research detailed in this thesis, the alarms were rarely used, this may be due to the staff being easily accessible to the patients through verbal responses.

A concept analysis exploring safety (Mollon 2014), although in an in-patient hospital context rather than an outpatient or renal/haemodialysis unit environment, suggests that feeling safe from a patient's perspective is an emotional state where patients' perceptions of care contribute to a sense of security and freedom from harm (Mollon 2014 p1727). The analysis revealed four aspects of feeling safe; these being trust, feeling cared for, nurse and family presence and knowledge, with the environment and relationships underpinning these four aspects. This highlights several aspects identified across the different themes within this research, but particularly the theme of being cared for by staff as a way of feeling safe, and supports the findings identified in this work for a haemodialysis setting, as well as an in-patient environment.

7.3.4 Discussion and Summary

The findings of this current study contribute towards the understanding of the three important aspects of care in this particular area. This understanding of direct patient care in a haemodialysis unit has begun to answer the research aims for this study. These three elements show the perceptions and experiences as three elements. These three important aspects of direct patient care in a haemodialysis unit align to other literature, suggesting that the findings can be regarded as reliable, as they are connected to previous research and literature.

Within the two frameworks presented in Sections 7.2.1 and 7.2.2, the findings of direct patient care are supported within these existing frameworks.

Within the PCP framework, the person-centred outcomes accommodate the findings presented here within their domains. The involvement in care, feeling of well-being and good care experience in particular can all support the findings of safe, comfortable and individualised care as key for haemodialysis patients in their experience.

Within the Fundamentals of Care framework, these identified elements of direct patient care are contained within the framework. The three aspects within the framework; physical, relational and psychosocial, all can incorporate these elements.

Within the core elements of care safety and comfort are specifically mentioned as key elements of patient care and therefore supports the findings presented.

Both these frameworks also suggest the individualised aspect of care being crucial as they both put the patient in the centre of the care and care experience and supports this particular finding identified in this research.

These components are not new in nursing care, but they highlight the key factors in haemodialysis care and the shared meanings by the different participant groups. Individualised, safe and comfortable care are the ideals for direct patient care in the haemodialysis unit and contribute to an understanding of what is valued as direct patient care in this context.

7.4 Individual Connections

There were many aspects to the connections or relationships within the haemodialysis unit, and they have been shown in the research to have an impact on direct patient care in this context. Defining these associations in this research as connections, rather than as a relationship was due to the nature and context of haemodialysis care and the varying degrees that patients and staff know or do not know each other in the unit.

The importance of a connection between the individuals who attend the haemodialysis unit is a significant finding within this research. Patients made connections with the other patients and both groups of the nursing staff in the unit who are specifically considered in this research. The connection between staff and patients is considered a key finding in this research and supports previously conducted research in this area. This research suggests that everyone can have an individual connection and that it is important for patients and their care experience for this to occur. Whether knowing and being quite familiar or being new and unknown, it is suggested that the importance of a connection between the patients and the people in the unit exists.

The individual connection between a patient and either a registered nurse or support worker facilitates care. The familiarity of each of these groups to each other, rapport,

trust and being interested allow for this individual connection. There is also a wider group connection between the patients who attend the unit, and the staff who work there. Boundaries to these connections were also identified, for example, clinical experience, job role and professionalism and ways to maintain the connections in the unit through gifts or remembering about each individual facilitated these connections.

The relationship between the nurse and the patient has already been identified through research as crucial for patient care within a haemodialysis setting, and relationships are viewed as important and crucial to the care delivered and experience (Vioulac et al 2016, Wilson et al 2015, Al-Ghabeesh and Suleiman 2014, Deal and Grassley 2012, Moran et al 2009b, Ashwanden 2003).

The connection is facilitated due to the regular attendance in the unit by the patients and staff, which allows the connection to develop as highlighted in other studies (Vioulac et al 2016, Bennett et al 2013a). The connection between them allows for care to be delivered (Hagren et al 2001).

Within this research, there was little on the over-connected relationships which are described by Moran et al (2009b), however the findings do suggest the presence of the connected relationship she describes as being crucial within the care delivery in the environment, and this connection can be facilitated in both ways of care delivery highlighted from this research.

Fingeld-Connett (2008a) defines one aspect of the caring process to consist of three attributes, one of these being intimate relationships. This intimate relationship was described to be protective and trusting. This echoes some of the findings of this research, which places a high importance on the relationships between the patients and the staff being a part of the caring process, where patients and staff share information about themselves. Similar findings have been identified with patient participants, indicating that staff being gentle and supportive regarding cannulation is a positive aspect of care in a haemodialysis setting (Chenitz et al 2014).

The Fundamentals of Care framework highlights the connection between staff and patients as part of care delivery in the relational aspect of the framework. The relationship or connection between the nurse and the patient is crucial for care delivery and requires to be achieved as part of patient care.

As part of this individual connection, there were four aspects which contributed to this larger concept. These were familiarity, being interested, trust and rapport. These four aspects are related and linked to each other and will now be discussed individually.

7.4.1 Familiarity

Familiarity was found to be important, as the staff and patients both highlighted that knowing each other was part of the care experience and care provided. The familiarity in the haemodialysis unit was on different levels, some knew others better or had known each other for longer than others, but still featured as key to the connection.

Patients and staff both wanted to know a little about each other, and liked when others took an interest in them as people, and also incorporated previous knowledge into new conversations. Patients would remember information which staff had disclosed, for example upcoming events, recent holidays or things they had been doing. They remembered information about their caregivers and would bring this up with them on another occasion. In research work by Yousefi et al (2009), considering in-patient care in Iran, they highlighted that patients seek familiarity as part of comfort in admissions. The requirement of a 'friend in hospital' was identified as an element permitting comfort to be provided, similar to the research here in the haemodialysis setting, which has a strong focus on familiarity between patients and staff and comfort.

This also happened from the staff's perspectives, both the registered and clinical support staff. Staff maintained the connections made from previous visits by following up conversations they had previously had. One patient was about to be a grandmother, and staff would ask regularly if she had become one yet.

Getting to know the patients was a theme identified from McCances' (2003) work, which also suggested that an important part of what is termed as activities of care was treating patients like individuals and knowing what was important to them. Within this research, which aimed to explore patients and their views on their experience of caring, several themes within the processes of care as described by McCance from Donabedian's concept, share findings with this research. McCance's term 'getting to know the patient' is in line with the findings here of familiarity and being interested within a much broader theme of an individual connection. Being treated as an individual is part of what was identified as an aspect of direct patient care in this research, but from McCance's work it is highlighted as an aspect which is important in patient care, rather than described as being part of the nurse-patient relationship.

When staff are not known or seen as unfamiliar to the patients, the patients do not make use of them in the same way that they would with more familiar staff. The patients would wait for staff they know better. This is about patients wanting to know who the staff are before they will ask questions or discuss issues, and not necessarily that the staff are not skilled, competent or able. Patients would prefer to wait for someone they know and with whom they have an existing connection.

Some patients said they would ask anyone in the unit for assistance, or depending on the situation would not wait for someone they already know. There was an understanding that all staff are there to help and that they will do what is needed.

Being familiar with each other is a long-term goal but also a short-term component to allow patients to feel safe and comfortable in their care.

7.4.2 Being Interested

Patients and staff both invested in being interested in each other as part of the individual connection as part of their time and care. Being interested is different to the previous aspect of being familiar, as when patients or staff were not known to each other, they would still be interested in this person and begin the development of some familiarity or connection, through engaging and being interested in the person in front of them.

This research outcome is similar to research results by Attree (2001), who identified that an aspect of good quality care was when nurses showed an interest in the patient and the social interaction was an important aspect between practitioners and patients.

When staff did not seem interested in the patients, patients had a negative caring experience, highlighting its value to them. Staff who were interested in the processes, and did not seem interested in the patient were regarded by patients and staff in a more negative way. However, their skills in the setting and knowledge still allowed patients to feel safe, comfortable and individual to some extent.

Despite this importance in staff being interested in the patients, some patients did not have a high value in this particular element. For these patients, they still required a connection with the staff but did not place a high value on telling the staff a lot about them and their lives.

Other research supports this finding of the importance of staff to be interested in patients in the haemodialysis setting. A small study interviewing eight patients who were waiting for a kidney transplant highlighted the importance to patients for healthcare professionals be good listeners, which formed part of their support on haemodialysis (Yngman-Uhlin et al 2016). This study reflects the results presented here, considering the importance of staff to be interested, for patient experience and care. Whilst this study only interviewed patients who were waiting for transplants and on haemodialysis, the research here did not consider this particular subset, and considered the inclusion of any chronic haemodialysis patient, which supports this previous research for chronic haemodialysis patients. Whilst the research conducted here could be considered not generalisable, the consideration of these results having been identified in previous research does add credibility to the results.

7.4.3 Trust and Rapport

The aspect of trust was about patients trusting the person/staff member, and also their clinical skills or competence. If patients did not trust staff, then they could feel uncomfortable during their time in the out-patient department on haemodialysis.

There was an element within the research that patients trusted the staff, regardless of their position, experience, and knowledge, unless they had a reason not to trust them through witnessing bad practice or a previous 'bad experience'. Staff wanted the patients to trust them so they would be able provide the direct patient care for them more easily.

This research supports previous studies by Berg and Danielson (2007) and Dinc and Gastmans (2013), who have suggested that a relationship between the nurse and the patient enables the possibility of trust, and that trust was viewed as something to strive for, by both patients and staff, however it was not achieved purely through striving. This result echoes similar results in other research. Rørtveit et al (2015) highlighted the importance of communication between the staff and the patient in the creation of trust in the relationship or connection and Aasen (2012a) highlighted the importance of trust for haemodialysis patients in the staff.

In a haemodialysis setting, Lovink et al (2015) established that trust in the nurse was a way of feeling safe on dialysis. Trust and honesty were identified as aspects of high quality nursing care (Thorsteinsson 2002). Trust was gained through feeling that nurses were clinically competent and by their attitude and manner. Patients do have expectations, realistic and justifiable expectations, that nurses are competent, compassionate, caring and can be trusted (Wiechula et al 2016).

Similarly, for pre-dialysis patients, staff encounters were identified to be important for facilitating the development of trust in the staff, which in turn supported personalised and individualised care (Nygårdh et al 2012a, 2012b, Nygårdh et al 2011). This work supports the research conducted here and adds to the body of work which considers staff encounters with haemodialysis patients to be important in the development of trust.

Rapport with the staff allowed the patients to feel happy and confident in their treatment and experience. If patients did not have rapport with staff, it impacted on the connection and potential relationship that they would have. It therefore affected how they viewed the care that they would potentially receive.

The research conducted here also highlighted that there were occasions where the patients did not feel they trusted the staff. This made them feel uncomfortable and uneasy when they were in their care, showing the importance of trust by patients but that it was not guaranteed. Similarly, patients have expressed that if they do not have a good relationship with the haemodialysis nurse, they find it more difficult to be treated and cared for by them (Hagren et al 2001).

7.4.4 Discussion and Summary

Individual connections are important within the haemodialysis unit, and are important in the delivery of direct patient care. The different aspects of connections have an impact on the care which patients want or require, and the development of these connections by all these groups are encouraged through caring practices.

Work by Lai et al (2012) has suggested that social support and informational support are sought from both healthcare professionals, as well as fellow established haemodialysis patients. This was a significant aspect to their dialysis experience, and echoes results found in this work, where there is a significance in the connections made with staff and patients for social and informational support.

The Fundamentals of Care framework highlights the aspects of trust, rapport, being interested and familiarity within their essential five elements required for a relationship to be established and the commitment to care.

The individual connection finding echoes elements within the PCP framework, particularly the person-centred processes of being connected with a patient, knowledge of them and their values and engaging authentically

Nurse-patient relationships have been well established in literature and caring theories (Morse 1991, Peplau 1952), especially in their importance to care delivery. Within nursing, relationships have been considered as a core and important attribute of caring (Brilowski and Wendler 2005) and this supports the findings presented here. Caring relationships incorporate trust, intimacy and responsibility and are essential in a caring relationship. There is a level of responsibility in the relationship

to the caregiver, the nurse or the support worker, and being near the patient so as not to abandon them.

To further discuss the connections uncovered through this research within the haemodialysis unit, research by Morse (1991) and Dierckx de Casterlé's more recent work (2015) will be used to explore the presented findings. Both of these concepts highlight the different levels in relationships, as different levels of relationships are a part of the care delivered in this particular unit and all levels are important.

The suggestions from this ethnographic research is that connection or relationship between the staff and patient is very important and impacts on the care experienced. Care is experienced as part of the connection experienced by the patients and staff.

Using the four types of mutual relationships determined by Morse (1991), these different types of relationships are all part of the larger connections theme within this research from the dialysis unit. The literature from Morse (1991) suggests that mutual relationships between nurse and patient depend on the involvement and intensity. These different mutual relationships are described as a clinical relationship, the therapeutic relationship, the connected relationship and the over-involved relationship. The relationship develops over time and interactions together, where the relationship progresses and becomes more connected or close. The connected relationship, where patients are viewed as a person first and a patient second, can be seen from the results as something which was both hugely important and valued in the unit by both the patients and nursing staff.

Dierckx de Casterlé (2015) suggest three levels of relationships which determines the level of care experienced. These are minimal or basic, professional and skilled companionship. Within this research, all three levels of relationships or connection occurred between staff and patients within the haemodialysis unit. There were first level functional relationships and second level, more individual relationships, where care needs are anticipated and a professional connection is achieved. The third level of relationship is considered to happen least often, and patients found when relationships were at this level, patients felt accompanied and supported due to the

empathetic presence of a nurse. The relationship is characterised by trust and equality, which echoes some of the findings within this research.

Within this haemodialysis unit, due to the longevity of a patient's attendance and the staff who work there, there were a large variety of different relationship levels if using this work to classify them. However, the third level of skilled companionship, where patients felt supported through this nursing empathetic presence, appears to be similar to the findings within this research.

Both of these categories and levels of relationships allow for the connections in the context of the haemodialysis unit, which allows for direct patient care to be provided by nursing staff through both active and passive care.

The patients in this study did not suggest they were dissatisfied with care on the whole; only one participant spoke of a nurse who she felt was cold and non-communicative and another who seemed disinterested. Staff and patients communicated throughout their time spent together in the haemodialysis unit. There was an understanding about when conversation was required and when it was not possible, due to other factors.

In contradiction to this, one study (Moran et al 2009b) has suggested that haemodialysis patients can be dissatisfied when nurses do not communicate with them as they wished. Moran et al (2009b) discuss that the patients felt nurses only communicated on a superficial or clinical level or did not have time to communicate at all. From this, the importance in the connection and communication between both parties in the haemodialysis unit is highlighted. However, within this research, patients did not appear dissatisfied with the level of communication and staff were not too busy to speak to them in this unit.

The support by healthcare professionals has been reported as important by male haemodialysis patients in previous research (Cormier-Daigle and Stewart 1997). Male patients in this study identified to rely on the assistance of supportive others to cope with their illness. This important support can be provided by healthcare professionals who come into contact with this patient group, which further highlights

the importance of a supportive relationship or connection with the staff in the unit, as it relates to patients coping.

Despite not having an established relationship with a patient, the nursing staff still strive or aim to make a connection. This was witnessed when experienced staff would meet patients they had not nursed before, e.g. when they moved back to the main unit from a satellite or when they came back from rotating to other acute areas which happened in the wider renal in-patient areas.

The importance of a healing relationship or connection and nurse expertise lies in their ability to connect with the patient in an authentic way, and be able to use their clinical knowledge and skill to manage the patient's care (Benner 1984). This relationship is termed in this work as an individual connection between staff and patients, and is an essential element for the Fundamentals of Care framework (Feo et al 2017b, Kitson et al 2012). This framework is in line with this particular finding, highlighting the importance of the connection between the patient and staff in the care process.

Other research has highlighted the importance of the staff connection with patients. self-reported questionnaires from 210 patients in an Australian tertiary hospital, patients identified that knowledgeable and communicative staff, timeliness of assistance and environmental support stood out as most significantly related to patient-perceived nursing care quality (Edvardsson et al 2017). Covington (2005) describes the shared nurse practitioner- patient relationship from a phenomenological-hermeneutic study, where mutual trust and sharing transcending connectedness and experience are vital for the relationship and in turn care.

The individual connections within the haemodialysis unit were an important aspect and facilitator of care delivery. The findings identified four aspects to the individual connection, which is supported by other research findings. The individual connection is crucial to the delivery of direct patient care and key within the model presented to illustrate the findings of this research (Figure 69).

7.5 Delivering Direct Patient Care in the Haemodialysis Unit: through Active and Passive Care.

This research has reconceptualised the way that direct patient care can be provided and delivered within the haemodialysis unit. The two terms have emerged from the analysis of the data, demonstrating the two ways in which direct patient care can be provided in this particular area. The delivery of direct patient care in this particular context is underpinned by the previously discussed finding, individual connection between the staff member and the patient, as this connection has an implication on the two types of care being delivered.

The terms used here to describe these two distinct concepts are active care and passive care, and they are both considered here in detail, with reference to other relevant literature.

7.5.1 Active Care

Active care is care delivered by way of either an active interpersonal engagement or through direct contact or involvement between the caregiver and the patient.

Through the process or delivery of active care, patients felt directly cared for; they felt comfort, felt safe and treated as an individual.

The crucial element of active care, which makes it distinct and different from passive care, is the element of direct involvement or the engagement, either physically or verbally, between the two individuals; between the registered nurse and patient or the healthcare/clinical support worker and patient.

Within this research, there are two distinct aspects to active care, but both highlight the engagement between these two individuals or groups. These are ‘time together’ and ‘verbal communication’, which will now be explored.

Time Together

This aspect of active care is clearly defined as having a focus on the shared time where patients are engaged with the staff in the unit. Here, time together focuses on

the nursing staff within the haemodialysis unit, both the registered nurses and the support workers, and the time they spend directly with patients.

The time together between these two groups on an individual basis was demonstrated in a variety of ways, predominantly when patients were getting prepared for haemodialysis, during haemodialysis treatment or when discontinuing haemodialysis. However, all groups of participants identified the importance and necessity of spending some time with each other during this regular dialysis experience. The time together was orientated around clinical tasks like dressings or the cannulation of the fistula¹⁵, or as one nurse demonstrated rubbing a patient's feet with cream when she was on dialysis. In this particular situation, at times there was no verbal communication, but they were spending time together in the haemodialysis unit.

The concept of spending direct time together aligns with the basic understanding from the literature on the Releasing Time to Care project and the original terms of direct patient care, as being 'at the patient or near the patient' (see Appendices 1, 2 and 3) but active care, in the form of time together, enhances this description further by suggesting there is a requirement of some engagement, involvement or inclusion of the patient in the care being provided.

Patients and staff acknowledge the difference between engaging with the patient, rather than just being nearby, and this research suggests it is not just the physical proximity or being beside the patient during their healthcare experience/encounter that is important and allows patients to feel cared for. This echoes the findings from Lai et al (2012) where patients seek time from staff, in the form of support, and to receive information from the staff when receiving treatment in the haemodialysis unit.

Various different scholars have suggested the nurse and patient spending time together or being there as a way of caring and have described this concept in various different ways (McCormack and McCance 2017, Berg et al 2007, Ford 1990). One way is through 'nursing action' and is described as an aspect of caring, either doing

¹⁵ The insertion of the haemodialysis needles into the fistula, graft or gortex access is described as cannulation.

for the patient or being with the patient (Brilowski and Wendler 2005). This term and description is similar to the idea presented here of active care, focusing on the involvement or engagement of the patient with the staff or staff with patient.

Similar to this idea of active care, Ford (1990) suggests a caring encounter is time together, engaged or involved, between nurse and patient. The literature suggests that nurses can be attentively present, when the nurse takes time to listen, give undivided attention and is able to focus on the needs of the patient. By taking time to listen, giving attention and focusing on their needs, the nurse is authentically present.

Berg et al (2007) identified that aspects of what they term a caring encounter could establish a caring relationship between a nurse and a patient in a medical ward. This caring encounter between a nurse and a patient included respect for each other and themselves, responsibility to reach out to each other and engagement. Again, this engagement aligns itself with active care from this research, albeit in a different patient context.

Engagement between nursing staff and patients also included non-verbal acknowledgements to each other, so does not require a verbal component. However, the verbal communication between them in this study was the other way of providing active care. This is further discussed in the next section within this discussion.

Time together, between patients and staff, was uncovered by Holloway et al (1998) as a way that patients would use as part of their strategy to pass the time when in hospital. Patients would also talk to each other as well as staff and patients who lived alone particularly enjoyed this aspect of their hospital stay. This research has echoed the findings within this ethnographic study that the time together with nursing staff, or with other patients, was an enjoyable part of the healthcare experience, and highlights its necessity, as there is a benefit to spending time with others when patients are in hospital environment.

Within the person-centred practice framework, presence is not purely about talking to and spending time with a patient, it is the ability of a nurse to be available to each patient, in that moment (McCormack and McCance 2017).

The Fundamentals of Care framework detail an aspect of the framework where the nurse requires to focus on the patient and provide undivided attention without being distracted. This element within the framework is needed for the delivery of care and crucial within this framework and supports active care where the staff are engaged and focused on the patient, however it does not lend itself to the findings of passive care.

Verbal dialogue/communication

The other component of active care is verbal dialogue or communication occurring between the caregiver and the patient. Within the haemodialysis unit, this was found to be delivered in many forms. These were identified and themed into; chat, humour, and banter and also in very ‘brief’ but valued ways.

Considering the mutual nature of communication, patients’ share in conversation should be taken more into consideration. A systematic review of literature on this highlighted a lack of value and neglect within the reviewed research (Fleischer et al 2009). The review highlighted the significance of other work which shows that communication constitutes an important element, which affects the quality of nursing care and influences patient satisfaction. Communication is a core element of nursing care and a fundamentally required nursing skill and this research supports the findings from this review of its importance in care. Verbal communication has previously been identified as an important aspect for patients as part of their haemodialysis experience and care. Previous research suggested that nurses do spend time talking with patients, but usually only when in connection with the machine or having clinical focus, leading to poor care experiences (Moran et al 2009b). The findings here highlight the importance of all types of verbal communication between nursing staff and patients, and it is a positive and important aspect within care experiences.

Humour was used by both patients and staff, which in other research has been shown to help establish rapport, trust, relieve anxiety and tension and ‘conveys unspoken emotional messages’ (McCabe 2004, Åstedt-Kurki and Isola 2001, Sumners 1990). All the participant groups in this research appeared to value highly the informal humorous exchanges between the patients and the nursing staff. This type of

communication can help to pass the time and deflect from mundane, routine hospital life and patients are frequently instrumental in creating such interactions (Jarrett and Payne 2000, Holloway et al 1998).

Both nurses and patients have been found to engage in humour during a haemodialysis session (Mallett and A'hern 1996). Research has previously suggested the deliberate use of humour during a haemodialysis session, and its importance as part of communication between the two was highlighted in this work, in line with the findings from the research conducted here. The value of humour was highlighted in other work as something which patients enjoyed when used by registered nurses. Humour showed caring and lightened the atmosphere for patients. This was considered an aspect of high quality nursing care (Thorsteinsson 2002).

A study which contrasts with the results presented here is Crotty (1985), who suggested that there was limited interaction initiated by the patients and the verbal interactions occurred more often when patients were addressed by the nursing staff. This was an observational study and did not consider the patient experience alongside these interactions. The research conducted in this study in the haemodialysis unit, and while it did not consider how often patients initiated the interactions, no patients reported dissatisfaction with the level of communication in the study.

In this research, communication was viewed as a key part of the routine and care provided in the dialysis unit. This contrasts to research conducted by Moran et al (2009b) when exploring communication in a haemodialysis unit. From patient accounts, it has been suggested that the communication was on a particularly low or 'shallow' level. The verbal communication expressed by patients in this particular study was focused around the physical and technical aspects of haemodialysis care. Patients expressed that staff did not come near them and communicate without this clinical requirement and that there was an unmet need in time with the staff to share concerns about illness and treatment.

One concept of caring, previously highlighted in Chapter 3, which correlates to the importance and significance of communication alongside the theme of individual

connection, is the idea of caring as an interpersonal interaction (Morse et al 1991). This term suggests that both parties communicate, trust, respect and are committed to each other. Emphasising that verbal communication has a significant impact on the patient and is integral to someone feeling cared for or the process of caring for someone.

The frameworks presented also highlight the verbal dialogic communication as part of their work supporting to the finding identified here. The frameworks do this in different ways. The Fundamentals of Care framework encompasses verbal communication as part of the relational elements of care.

Verbal communication also features within the PCP framework, particularly in the engaging authentically and holistic care aspects.

Presence

The concept of active care, including time together and verbal communication incorporates the term ‘presence’, a concept which has been explored within the nursing literature in some depth. The findings in this study emphasise the importance of presence as a concept of engagement, particularly between the nurse and the patient and its role in caring.

The term presence is thoroughly discussed in nursing literature, but this piece of ethnographic research suggests the importance within direct patient care or caring with the presence of a registered nurse or healthcare support worker. Specifically, within this concept described as active care, presence is demonstrated through an active engagement with the patient, and requires more than simply physical proximity, as the important aspect of a caring presence.

Various scholars have suggested that nursing presence has a focus on the interaction or encounter between the nurse and the patient.

Hessel (2009) has defined presence in nursing to be

‘a holistic and reciprocal exchange between the nurse and patient that involves a sincere connection and sharing of the human experience through active listening, attentiveness,

intimacy and therapeutic touch, spiritual exploration, empathy, caring and compassion, and recognition of the patient's psychological, psychosocial and physiological needs' (Hessel 2009 p281).

This definition suggests the presence, or active caring position of a nurse (or a support worker) can allow a connection and sharing of experience.

In relation to direct patient care, the seminal work of Benner (1984) highlights 'presencing', a way in which nurses can be with and care for a patient. Benner (1984) established presencing of the nurse, where it was the art of being with a person or patient, without the need to be doing anything to them, which has significance against this finding of active care.

Melnechenko (2003) aligns with the research, as it suggests that there is an importance on the staff spending time and being involved with the patients.

'Presence does not require more time, rather than a willingness to focus on really being there and being involved when with another' (Melnechenko 2003 p19).

This is similar to the concept suggested here of active care being the findings of time together and verbal dialogue and communication.

Brilowski and Wendler (2005) in their evolutionary concept analysis of caring identified, three actions which align with the concept of active care presented here. Nursing care, touch and presence suggest these nursing actions as part of caring, but within this it is not clear whether the actions require to have a particular focus on engagement between the staff member, usually a nurse, and a patient. They describe presence as

'occupying the same space as the patient, listening carefully, allowing time to share' (Brilowski and Wendler 2005 p644).

Nursing care entails the actions and interactions primarily focused on physical care and touch as a non-verbal communication.

Within this research, this definition by Brilowski and Wendler (2005) of the concept of presence aligns itself within both aspects of the key finding of active care, incorporating presence as both time together doing a variety of clinical or non-clinical activities and verbal communication between the staff member and the patient.

Presence is more than simple nursing action (Doona et al 1997), it focuses on the patient through a unique, intersubjective encounter. As it is described here as an encounter, it suggests the engagement in the process from the patient and the nurse.

The importance of engagement and time together described as active care supports Easter's (2000) work and their four aspects of presence. This explanation of physical presence, despite being focused on close proximity, requires being there with the patient through touching, doing or movement, which is important, as the concept defined here as active care is time together and verbal communication.

Close physical proximity is viewed as an essential aspect of the process of presence and includes engaged availability, affectionate touching and attending to personal needs of patients, which allows a meaningful exchange between the nurse and the patient and giving full attention to the patient (Easter 2000).

Nursing care has been suggested to be more than providing a level of care, it requires 'being present in the moment of crisis and need' (Zyblock 2010, p123). This suggests the importance of an engagement and interaction between the nurse and the patient and highlights the importance of active care.

Fingeld-Connett (2006) defines presence as an interpersonal process that is characterised by sensitivity, holism, intimacy, vulnerability, and adaptation to unique circumstances. This metasynthesis highlighted that presence is a 'helpful, beneficial and positive phenomena', however the focus on the interpersonal aspects of the engagement suggest that passive care would not be part of 'presence', due to the lack of engagement, but the findings suggest here that it does also have a helpful, beneficial and positive outcome on patients and patient care.

McKivergin and Daubenmire (1994) suggest three levels of presence – physical presence, where the nurse is ‘being there for the patient. Psychological presences (‘being with’), allow the patient to feel comforted, but also suggests the requirement for physical proximity. All three levels of presence suggest being with and doing with, suggesting some engagement as similar to the concept presented here of active care.

In the haemodialysis unit, touching was not observed in a non-clinical task related situation, but touching is suggested as an important aspect of ‘presence’ in this literature. Touching between staff and patients occurred through close proximity tasks like blood pressure checking and when needles were being inserted or removed. These tasks were with a clinical focus or purpose, whereas hand-holding or touching was not observed in the research.

Within this research, it is suggested that the definition and value of presence is physical engagement and is achieved through active care. The literature on nursing presence focuses on two aspects, presence being an interpersonal process and the close proximity of the nurse and the patient. Caring and human presence have overlapping components; sensitivity, expert nursing practice and reciprocal relationships (Finfgeld-Connett 2008a, 2008b, 2008c, 2008d).

Godkin (2001) has a hierarchy of healing presence, which follows on from work by Doona et al (1999), whose six elements of presence have a hierarchy and are not equal. Ford (1990) describes being ‘attentively present’ when a nurse takes the time to listen, gives the patient her undivided attention and focuses on their needs. This is similar to the definition presented here of active care, where there is engagement between the patient and the caregiver.

One way of describing active care, suggested in the work by Watson (1999) and cited in Holopainen et al (2012) is where a caring moment entails genuine presence and connectedness between two human beings. This presence and connectedness suggest the engaged encounter highlighted in active care. This caring encounter does not acknowledge that care can still be delivered outwith the encounter i.e. as suggested by the concept of passive care.

Presence is also described as a holistic nursing intervention (Hess and Klebanoff 2014). They state that presence is a quality when being with a patient.

‘Consciously staying in the present moment, open to what’s beyond preconceptions and habitual and historical ways of making sense. Being present involves self-knowledge, willingness to know others, awareness of one’s internal and external environment, and the ability to appreciate the uniqueness of oneself and the patient’ (Hess and Klebanoff 2014 p48).

The willingness to know others which Hess and Klebanoff suggest is part of presence also aligns with being interested as part of the individual connection finding.

Active care follows the more traditional understanding of time together, by physically doing something or having direct contact with a member of staff. This incorporates the aspect of verbal communication between the nurse and the patient.

Work with cancer patients suggested that professional caring

‘almost always includes some action, doing for the patient or being with the patient (Halldórsdóttir and Hamrin 1997 p125).

This work also used the term active caring to describe these caring encounters when considering professional caring in a cancer setting.

McCormack and McCance (2017) suggest in their PCP framework that presence is more than being physically present, presence in Person-centred Practice is captured by Benner in her 1984 work, which suggest that it is the art of being with a person without doing anything to a person. McCormack and McCance (2017) suggest that presence can be interpreted in terms of being attentive and being available. The aspect of availability is discussed in relation to these findings in the following section, as it is described as an aspect of passive care and not active care. Physical presence in this research does not particularly highlight the engagement between the nurse and the patient and therefore does not always suggest care activities occurring.

7.5.2 Passive Care

Direct Patient Care can be delivered through Passive Care, such as staff being available and visible, but not engaged with the patient (not an engaged interpersonal process and not merely ‘presence’).

The key findings from this research suggest that direct patient care can also be provided through passive care, a term developed through the analysis of the study’s findings, which contrasts with a lot of the literature already detailing care as an active engagement or encounter.

Passive Care is the way care can be delivered, where a patient remains feeling cared for, despite staff not being actively engaged with that particular patient. Through the delivery of passive care, patients felt safe, individual and comfort.

Within the haemodialysis unit, this happened in a variety of ways. Staff would be located at the desk, either writing notes or on the phone, organising equipment and getting things ready for the next patient group, tidying and restocking, or actively engaged with other patients.

There are two themes within passive care, visibility and availability, but both differ from active care, as they do not have an engagement through an interpersonal process the opposite of active care. Passive care identifies that staff being visible and available for patients, despite not being in close proximity or doing something directly to or with them still allows patients to feel or be cared for, and staff to feel they are also caring for these patients in these passive ways.

Visibility

It was identified from this research that the visibility of the staff occurred through staff being at the dialysis chair’s side and within the dialysis room but in a non-engaged way with a patient. Despite the lack of interpersonal interaction (an interpersonal interaction is defined here as an aspect within active care), patients can see or know there is staff present in the room and therefore remain cared for.

Patients know the staff are within the room or dialysis unit, as they can hear them and know the procedure in the unit for staff being in the room at all times. This staff

visibility is akin to presence in some of the literature, but the definitions and concepts do not include the lack of physical proximity that was pronounced in passive care.

Availability

Availability in this research is described as staff being able to react or be able to do something for the patients if required. The importance of staff to be considered to be available by the participants or the ability to call them impacted on the care that patients experienced.

The importance of staff to be available was presented in research by Yngman-Uhlin et al (2016) in their work which interviewed eight haemodialysis patients who were on the transplant list. This research did not establish or consider if patients were on the transplant list, but still established similar findings for the haemodialysis patient population.

Staff are able to be directly caring for a patient through providing active care, whilst the other patients at the same time still feel cared for during this process, in a passive way. Key to this finding of passive care is the lack of interaction between patients and the member of nursing staff while can still take place.

Henderson et al (2007) has suggested that patients within in-patient areas also put a high value on the availability of nursing staff, which translated to feeling 'cared for' in the ward environment. Patients understood when nurses could not spend time with them, but were dissatisfied when nurses were not available to respond to their immediate needs. This highlighted that nurse-patient interactions still allow patients to feel cared for, even when the interactions do not appear to be part of a connected relationship. This piece of research suggests that the availability and visibility of the staff, when not directly interaction with patients still allows for a feeling by the patients of being 'cared for'. The work does also suggest a dissatisfaction when nurses are not readily available, which suggests the availability and visibility as part of passive care in this research as something that the staff do as part of their caring actions (Henderson et al 2007).

Although presence as a concept is already highlighted as featuring within the concept of active care, it also has some aspects from the literature which suggest a component of presence to align with passive care. The physical proximity of staff, of varying degrees, within this research is one dimension of presence from the literature which supports elements of passive care. The lack of engagement between the two individuals, which is a feature of passive care, is also suggested from some explanations of presence.

Some presence literature does not directly suggest the requirement for physical engagement for presence to be felt and patients to feel cared for. Within the term of passive care from this research study, the presence of staff within the unit or room is part of both availability and visibility of staff. The findings in this study emphasise the position of presence in the literature already published; the importance of presence as being an aspect of care which is not predominantly focused on an active engagement. The focus is instead on the physical proximity, without requiring any active engagement between the nursing staff and the patient.

Brilowski and Wendler (2005) in their conceptualisation of caring do not have an attribute which is similar to passive care. Their definition does not allow for the action of 'passive care', the nursing presence where there is no active engagement, but patients still feel cared for. In the presence literature, nursing presence has a focus on 'being there' or physically there, however very little of this literature suggests that it can be delivered by means other than interpersonal engagement or active care.

The literature on presence has focused on a direct link between being there and interpersonal engagement between the two parties, however this research has suggested that being there, particularly at a distance and not engaged with the patient can still allow for a patient to be cared for, through their availability and visibility to the patient without this direct engagement.

Osterman and Schwartz-Barcott (1996) have 4 levels of presence or 'being there'. These are presence, partial presence, full presence and transcendent presence. This finding of passive care has some similar aspects of 'being there', described by

Osterman and Schwartz-Barcott (1996), who defined two levels of presence, presence and partial presence, which do align, although here they suggest that they both require the physical proximity between nurse and patient.

Osterman and Schwartz-Barcott (1996) have suggested presence to be

'being there in the context of another. Nothing more is implied' (p26).

This concept of presence is where no interaction is taking place, the nurse may be physically (in body) with a patient while at the same time may be focusing on the self or other object in the environment (Osterman and Schwartz-Barcott 1996).

Partial presence is where the staff is physically there in the context of another person, but are focussing their energy on a task and not directly focused on the patient.

Partial presence has a crossover between the terms of active and passive care. Using Osterman and Schwartz-Barcott's (1996) term partial presence, if the task is directly involving the patient, e.g. dressings, wound care, permcath, assessing fistula, then it is an aspect of active care, as there does not require to be communication at all points of this interaction. Partial presence in the case of passive care would be examples where the nursing staff are looking at the machine, doing the checks, needle checks, or patient folder viewing in the presence of the patient, but not interacting or focusing on the patient. Osterman and Schwartz-Barcott describe this as the patient being in the background whilst the task is in the foreground (Osterman and Schwartz-Barcott 2010).

There are also two other ways of being there or presence as suggested by Osterman and Schwartz-Barcott (2010, 1996). These other aspects are 'full presence' and 'transcendent presence'. Full presence is where the nurse is focused on the patient and is interacting, which supports the term or concept of active care from this research.

Osterman and Schwartz-Barcott (1996) suggest these as different ways of being with the patients, with one type of presence being purely physical and without an interpersonal engagement. This definition of one type of presence would suggest

that, due to the lack of interpersonal engagement, would be similar to aspects of passive care within this research, although they have different outcomes. Osterman and Schwartz-Bartcott (1996) suggest this method of presence has a negative outcome on the patients and can promote feelings of isolation, withdrawal and increased anxiety. The findings of the research presented here suggest that passive care, in contrast to Osterman and Schwartz-Barcott (1996)'s definition of presence, which despite having similar attributes, has a positive outcome and allows positive feelings from patients as feeling cared for, comfortable and safe.

This way of being there for the patients by Osterman and Schwartz-Barcott (2010, 1996) does not reflect the relationships already established and the caring environment found within the haemodialysis unit, an out-patient environment.

This view of presence also does not allow for the finding from this research of passive care. The research here suggests that the direct and physical closeness is not necessary for patients to feel cared for, through this concept of passive care. The staff being with other patients and engaged with them also allows for the group to feel cared for through the caring for others, and Osterman and Schwartz-Barcott (1996) do not cover this within their four aspects of presence.

Interestingly, Finfgeld-Connett (2008b) has compared and synthesised the terms of presence and caring and suggests that presence and caring are both similar processes. These comprise of an intentional therapeutic process and are characterised by expert nursing practice and intimate interpersonal sensitivity.

Schluter et al (2011), through interviews with nurses (both registered nurses and enrolled nurses¹⁶) suggested that good nurses are those who work in proximity to patients providing total patient care. In this work, proximity is understood as the physical distance between nurses and patients. This proximity focuses on hands-on care, but does not suggest whether the patient is actively involved in the tasks.

¹⁶ Enrolled nurses is a term used to personnel who are enrolled by a nurse registration board and may practice under the supervision of a registered nurse

This theme or concept has two sub-themes, the nurse (or support worker) being visible to the patient (through presence, but not necessarily in a close proximity, so different from 'presence' literature, as sometimes it is distant) and perceived availability to the patient.

Patients felt cared for when the staff checked the machines, stocked trolleys or wrote notes at the desk in the room, despite not being actively engaged in the process. One way of delivering passive care was the act of checking machines and settings and needles not being dislodged occurring while patients read their books or watched the television. Passive care is different to active care, however its underpinning principle is the lack of interpersonal engagement between the two, while still permitting 'direct patient care' to be delivered.

Osterman and Schwartz-Barcott (1996) cited work by Frey (1985) where one way of being present was where a nurse, during a patient's process of labour, occupied her time in a patient's room by reading. This scenario suggested that this nurse's presence was not felt and whilst she was physically there, she was not felt to be available to the patient. This example illustrates an aspect of non-engagement with a person within close physical proximity which was not shown in this study, as the patients in this study felt that despite staff being occupied by other tasks, both clinical and non-clinical, they were still available and visible, allowing the patient to feel cared for (Osterman and Schwartz-Barcott 1996).

Hegedus (1999) found when testing a scale of nursing caring behaviours there was agreement on one middle range of caring behaviour; 'the nurses comfort me by their silent presence'. This silent presence suggested from this scale of nursing behaviours that the physical proximity is crucial, as well as the engagement. This is demonstrating the passive care aspect as a valued part of nursing practice.

McCance (2003) suggested activities of care (process) which suggest feelings of wellbeing and patient satisfaction (outcome). From this work, McCance suggests that there is a linear link or relationship between the structure, process and outcome.

There are eight different activities of care, which predominantly fit within the active care concept/theme suggested in this research. McCance (2003) in suggesting caring processes does not effectively capture any caring behaviour or activities which fit with the concept of passive care. Passive care does not account for the physical proximity and lack of engagement which still allows for the patients to feel cared for through this caring process/method of care delivery.

One aspect from McCance (2003) which corresponds with the concept of passive care from this research is the activity of 'being attentive' as one of the processes of care. McCance describes attentiveness as being physically present and visible, drawing parallels from both the active care theme of time together as well as the passive care theme of being visible. However, McCance (2003) suggests this attentiveness is superficial and relates to the 'nurse being willing and available to do whatever she can' (McCance 2003, p110). Within this research, being physically available and physically visible are attributes to the larger concept of passive care.

It seems then, that presence or close proximity are important for caring and whilst it is not the whole part of caring, and that this close proximity is not necessary all the time, it is a central defining concept. Despite the huge technological presence in the haemodialysis unit, caring is still felt through the availability and visibility of nurses.

Another aspect of Finfgeld-Connett's (2008a) caring processes is 'interpersonal sensitivity'. Within this attribute of interpersonal sensitivity, there is a suggestion that it is made possible by being 'physically and mindfully present' (Finfgeld-Connett's 2008a, p119) and 'being emotionally open and available', This study's findings go further than this, illustrating that the caring process is not only demonstrated through touching, eye contact, listening and verbal reassurances; care can be delivered through passive care through staff being visible and available, but not directly engaged as Finfgeld-Connett (2008a) has suggested.

Finfgeld-Connett (2008a) also suggest an attribute of the caring process to be 'expert nursing', however from this research, the expertise, technical knowledge or experience is not always a positive influence on the caring process. Doona et al (1999) suggest six features of nursing presence: uniqueness, connecting with the

patient's experience, sensing, going beyond the scientific data, knowing and being with the patient. The findings from this research is that presence can be described through the availability and visibility of staff, that of passive care, as well as the engaged interpersonal processes and active care.

Doona et al (1997) explore presence and suggest that it has a focus on the patient, although not the physical proximity, but is intersubjective between the nurse and the patient. The finding in this research is that passive care suggests that the distant presence of staff and their perceived availability to attend to patients when they are in need or require assistance or help is part of the caring process in the haemodialysis unit.

The lack of engagement from staff during a patient's time in haemodialysis does not detract from the caring process, engagement between the two individuals is not the only way that care can be delivered. Hegedus (1999) found when testing a scale of nursing caring behaviours there was agreement on one middle range of caring behaviour reported by patients, where patients felt comforted by the silent presence of nurses. This suggests a lack of interaction, but a feeling of being cared for nonetheless, although we cannot understand what the presence means, or if an existing relationship between the nursing staff and the patient is needed to elicit this feeling.

Paterson and Zderad (1976) in part of their humanistic nursing study describe presence as

‘A mode of being available or open in a situation with the wholeness of one's unique individual being; a gift of the self which can only be given freely, invoked or evoked’ (Paterson and Zderad 1976 p132).

Paterson and Zderad (1976) suggest that nursing activities bring a nurse and a patient into close physical proximity, but this in itself does not guarantee genuine intersubjectivity, in which a human relates to another person as a presence rather than as an object. Covington (2003) suggests that caring presence is an interpersonal, intersubjective human experience of connection within a nurse-patient

relationship that makes it safe for sharing oneself with another. The nurse brings a conscious awareness (intentionality) and is available and attentive in the moment to provide opportunity for deep connection in the relationship.

Covington (2003) further argues that caring involves an affective component, not identified in definitions of presence. This places presence within the context of caring and provides a way to view the phenomenon as different from the individual concepts.

There is little within the Fundamentals of Care framework which supports the finding of passive care. The framework does not appear to provide an explanation to the value identified in the staff visibility and availability which does not have an engagement of focus directly on the patient.

A key aspect of the person-centred process detailed in the Person-centred practice framework is related to these research findings; that of sympathetic presence (McCormack and McCance 2017), which describes an achievable way of being with patients in line with person-centred practice. Sympathetic presence is an engagement that recognises the uniqueness and value of the individual, an engagement which reflects the connectedness between a nurse and a patient.

Sympathetic presence is dependent on knowing the patient, and having insight into their beliefs and values, which suggests a significant value on the finding of 'individual connection' as part of this research. Being sympathetically present, as defined in the framework suggests, the appropriate response to cues through providing reassurance and showing concern.

7.5.3 Discussion and Summary

The terms active and passive care divide how direct patient care can be delivered in this context, whilst patients can still feel in receipt of individualised, safe and comfortable care. Using active and passive care as terms, they each highlight the different ways care is provided and demonstrate the different processes. Active care centres on the engagement and involvement between the two people involved, staff and patient, and is more than just the physical presence of a member of staff. Passive

care can occur when there is no engagement, but there is the availability and visibility of staff to patients and this is defined by more than physical proximity.

The Fundamentals of Care framework, particularly the elements of focus as part of the relationship do not allow for the finding of passive care. The PCP framework whilst does accommodate the finding of staff being visible through sympathetic presence, does not allow for the full concept of passive care as identified in the findings presented. The ability for care to be experienced through the availability and visibility of staff does not fit within either of the two presented frameworks although some aspects do align with different elements – just not altogether.

Considering these terms against the PCP framework and the Fundamentals of Care framework, neither consider to the extent presented here the care which is experienced through staff availability and visibility, and have a focus on the more active and engaged process of care delivery.

7.6 Direct Patient Care is the Whole and a Combined Process

One of the key aims of the research was to establish if there were differences between the three groups in their perceptions and experiences of direct patient care.

Establishing and exploring from the patients' perspective what direct patient care is in the context of the haemodialysis unit has highlighted DPC as more than being 'at the patient or near the patient' as the RTC run chart and literature suggests. Whilst caring viewed as central to nursing practice, many have explored the ideals which make up this term, and this research adds to the literature on care, describing and understanding what direct patient care is in this particular clinical area.

Patients suggested that direct patient care was much more than staff carrying out clinical tasks or skills beside them. It encompassed feeling cared for, through reassurances and having a chat, from their arrival to the unit to going home. The connections between the patients and the staff and also the wider haemodialysis unit also are part of the direct patient care concept.

This finding suggests that as patients experience direct patient care as their entire experience in the haemodialysis unit, it is not primarily focused on the amount of time with staff and encompasses many aspects of interactions or non-interactions, as well as the demonstration of clinical and technical skills.

Weiss (1988) proposed a model in which care consisted of 3 behavioural components; verbal caring, non-verbal caring and technically competent behaviour. This suggests that nursing care is more than technical skill and must also incorporate verbal and non-verbal caring behaviours to have therapeutic value, but that in displaying any of the components that ‘the property of nursing care only is present’. This supports the findings here that the patients’ view of direct care incorporates different aspects of nursing practice to provide care, but does only focus on the nurse and not the patient or the clinical context in this model.

This perception from patients contradicted the staff’s understanding of direct patient care, as it was perceived by both registered nurses and clinical support workers as having a primarily clinical or task focus with a secondary focus on other aspects. This crucial difference in how DPC is understood highlights a discrepancy in the way both groups may approach care in this environment and this newly understood and shared understanding of DPC, as being individual, comfortable and safe, can be achieved by nursing staff for patients despite the different approaches to it.

Kyle (1995) suggested from reviewing quantitative studies on caring using the Care-Q instrument that patients and nurses have different perceptions of caring, which is supported by these findings, as both staff and patients have presented ‘direct patient care’ in different ways. Papastavrou et al (2011) concur that there are differences in the perceptions of caring and caring behaviours between nurses and patients.

Andersson et al (2015) explain this somewhat, in that a nurse’s view of caring is contextually intertwined, but does not question whether this safeguards the patient’s best interests or delivers person-centeredness.

The findings within this research suggest that care in this environment is not purely placed on the staff’s ability related to clinical skills and technology. However,

Bevan (1998) suggested that the dialysis nurse is precariously placed in becoming enframed by technology, with dialysis nursing being considered a series of techniques that anyone can learn. This study does not suggest that this has occurred in this particular setting. The care in this environment is not restricted to these aspects and encompasses many aspects of dialysis related and other interpersonal activities.

Presence, touch and listening are suggested to be part of a caring conversation (Fredriksson, 1999). Fredriksson suggests there are two ways to have a caring conversation, with a connection or with contact. Both of these approaches suggest that physical presence and engagement are important, but are delivered in different ways and to different degrees. This research synthesis does not allow or suggest a lack of engagement to be a factor in care, so the findings in Fredriksson's research of passive care are not echoed in this research, but the active care, through engagement in varying ways and degrees is in line with this synthesis.

This research has highlighted the two ways in which direct patient care is delivered or experienced in a haemodialysis unit, being either actively or passively delivered. The importance of the individual connection between the member of staff and patient facilitates the delivery of these two processes of direct patient care: active and passive care.

This particular finding highlights the similarities and slight differences in what patients and nursing staff perceive as part of care delivery. From considering the different perspectives and experiences in this research, the shared understanding of direct patient care has been established, however there are different ways of explaining them from the research, dependent on the participant group.

Interestingly, the patients consider care to include the whole process and experience of haemodialysis, as opposed to the staff, who consider care to be made up of the more clinical tasks, with less focus on the other more relational elements.

The shared understanding, despite the different ways in explaining direct patient care, highlights the value in exploring this term by including all the people involved

in this term. Care is a shared or jointly constructed thing between the nurse or support worker and the patient and therefore all these parties need to define what comprises this term together. By only considering one group's perceptions of direct patient care, the other views are not considered and therefore difficult to understand from only one but important perspective.

This concept model, shown in Figure 69, illustrates the important findings and aspects of this research which lead to direct patient care being experienced as an individualised, comfortable and safe experience through two different ways.

The model presented from the findings from this study draws on elements from both the Fundamentals of Care and the Person-centred Practice framework, introduced in 7.2. However, as neither model was an adequate explanation for the findings of this study, a conceptual model was developed, which drew on the elements of these frameworks. No attempt was then made to attenuate the existing models, but the data in the study led to a presentation of this new model of direct patient care.

7.7 Considering the existing frameworks against the findings

Considering the main findings of this research, and exploring the concept of direct patient care against two key frameworks in care delivery and patient care, the two existing frameworks presented did not consider the findings adequately, so a new conceptual model was devised and is now shown again in Figure 72.

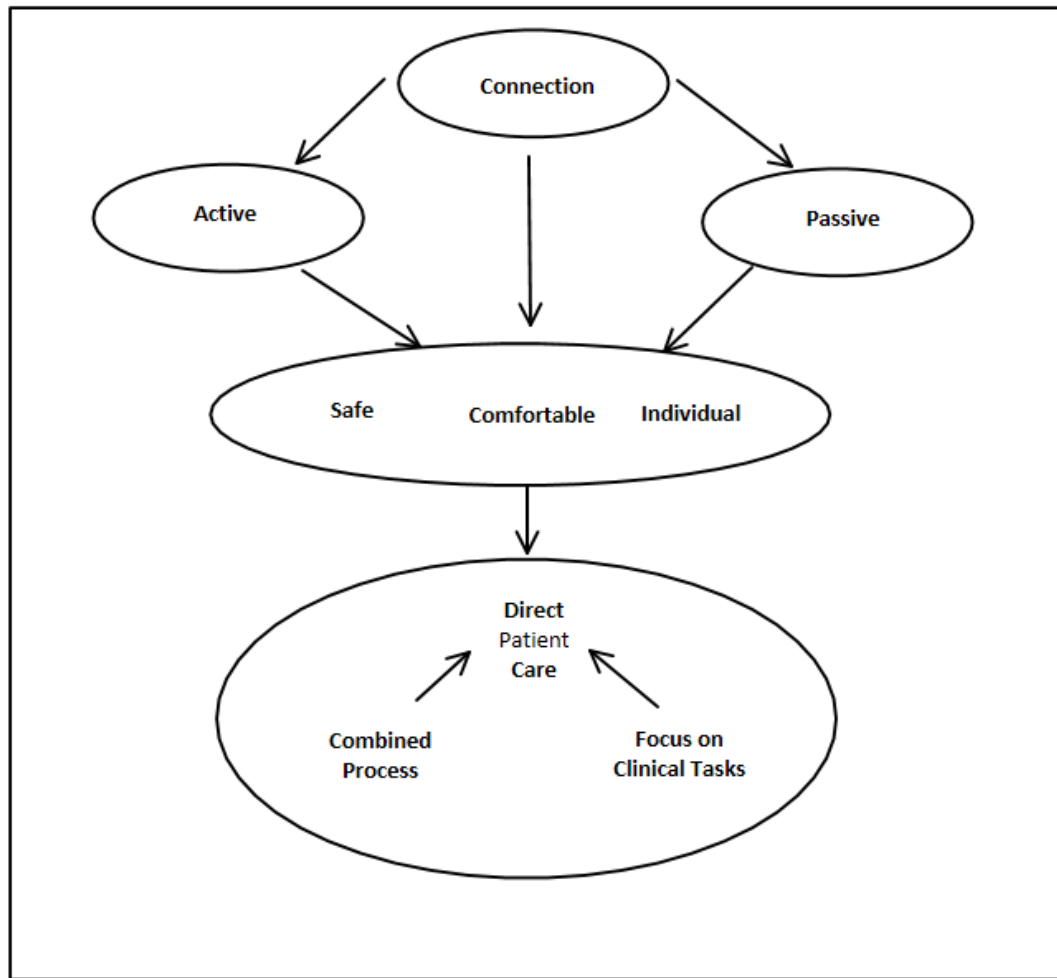


Figure 72: Conceptual Model of Direct Patient Care in Haemodialysis

Both Kitson's Fundamentals of Care framework and McCormack and McCance's work do not fully explain the findings in this research, however, there are aspects which do draw some similarities.

Fundamentals of Care framework shows the important aspects of the relationship between the nurse and the patient, and this supports the findings presented here, where the connection between the patient and the nursing staff facilitates the care delivery. This positive and trusting relationship is the basis for the delivery of care (Feo et al 2017b).

Neither of these two frameworks support the findings of passive care, however, both have elements which do support aspects of the findings, which have been illustrated throughout the discussion.

The elements of the integration of care; physical, relational and psychosocial, from the framework (Feo et al 2017a, 2017b) are the ways in which patients' needs are met and inform how the nurse can support and meet these needs within a care encounter. This care encounter does suggest there is a focus on the active care activities, rather than the ability to deliver care in a passive way, which does not support the findings within this research. The passive care elements from this study cannot be understood using this framework (Feo et al 2017a, 2017b, Kitson et al 2010, 2013a); the importance of the relationship, for both nurses and support workers with the patients is clearly identified, with similar aspects, however it does not suggest that care can be delivered within this passive way, as identified in the findings.

The McCormack and McCance (2017) framework of person-centred practice also supports elements of the findings, however, there are elements which are not fully explained. A key aspect of the person-centred process detailed in the Person-centred practice framework is related to these research findings; that of sympathetic presence (McCormack and McCance 2017), which describes an achievable way of being with patients, in line with person-centred practice. Sympathetic presence is an engagement that recognises the uniqueness and value of the individual; an engagement that reflects the connectedness between a nurse and a patient.

Sympathetic presence is dependent on knowing the patient, and having insight into their beliefs and values, which suggests a significant value on the finding of 'individual connection' as part of this research. Being sympathetically present, as defined in the framework, suggests the appropriate response to cues through providing reassurance and showing concern.

Within the findings presented here, care has been identified as being experienced and can be delivered when staff are not sympathetically present as the PCP framework suggests (McCormack and McCance 2017). The Fundamentals of Care framework also focuses on the relational elements of care but also identifies the basic aspects of care which do focus on more clinical aspects, alongside safe, comfortable and individualised feelings (Table 9).

Patients felt cared for through the availability and visibility of the nursing staff, not just through their active engagement or simply being present, therefore neither of these frameworks fit the findings presented.

The model conceptualised here following this research draws on these existing frameworks, rather than further developing them.

7.8 Summary of Chapter

As direct patient care is a term which has significance in the RTC and healthcare efficiency literature, its reconceptualisation in this study has suggested that there are more aspects which impact on the feeling of cared for in a haemodialysis unit than actively spending time with patients.

The research has identified direct patient care as being composed of three elements; individualised care, comfortable and safe. These three elements are well researched within the nursing literature, and this research supports previous work which has identified these aspects as important, although not necessarily under the term direct patient care.

These three elements combined are regarded as the elements required as part of direct patient care in the haemodialysis unit. These three elements require to be achieved as part of the new way in which care delivery has been conceptualised; active or passive care.

Delivering direct patient care was conceptualised in two ways; active and passive care. Both of these terms, derived from this research, have shown that direct patient care considers existing literature on caring and presence.

Active care being time together and verbal dialogue aligns itself with the traditional elements of the presence literature. The research suggests that passive care can be delivered through staff being available and visible, but not necessarily from an engaged or close proximity perspective. Passive care is also underpinned by an individual connection between the staff member and the patient. Delivery of care in both of these ways combines the three elements of direct patient care, as these three

aspects can be experienced through both active and passive means by the nursing staff in the haemodialysis unit.

The adjacent finding of an individual connection has suggested from this research that a connection requires familiarity, being interested, trust and rapport, which can have a significant and positive effect on the patient. The key findings discussed here show the value in the connections within the haemodialysis unit, and the positive outcome of being available and visible within the care area for patients, even whilst not having an active exchange.

The understanding of direct patient care having a different value than the initial description from RTC indicates the discrepancy between the value of time with staff compared with the entire experience and various aspects which are considered to define the provision of care. The understanding of the whole care experience for haemodialysis patients and all of its elements can provide staff with the knowledge that all aspects impact on the patient experience when attending for treatment. Highlighting the lack of focus on purely the clinical or technical skills and the inclusion of relational and other elements can be used for staff to consider how care is delivered and experienced and how it will impact and affect patients.

Considering direct patient care as a whole process, patients and staff described the term in different ways. Staff had a more task focused approach, but still considered the wider aspects, albeit in a secondary capacity. Patients considered all aspects of their time in relation to their treatment as part of their direct patient care experience.

Finally, to conclude, a concept model has been devised to further illustrate the different aspects of direct patient care in the haemodialysis unit. The development of this concept model was due to findings not fitting with the previous frameworks and models presented.

Chapter 8 Conclusion

In this final chapter, the research is summarised by answering the research aim and questions, considering the limitations of the work, implications for practice and policy and then concludes with future research.

8.1 Summarising the findings and answering the research questions

The aim of the study was:

To gain an understanding of patient and staff perceptions and experiences of ‘direct patient care’ within one large in-hospital haemodialysis unit.

The research presented in this thesis from the ethnographic study conducted grants an understanding of patient and staff perceptions and experiences of the concept of direct patient care.

Specific questions focused on establishing what patients want and value as direct patient care, and their perceptions and experiences of this, and the two staff groups’ views on what they regarded as direct patient care activities.

The research presented in this thesis has established what direct patient care is in one haemodialysis unit, exploring registered nurses’, support workers’ and patients’ thoughts on the concept of direct patient care and how it is experienced and achieved in this setting.

Direct patient care in the haemodialysis unit was made up of three things, patients feeling individual, comfort and safe. Crucial to this was the individual connection between the staff and the patients, which was required to facilitate direct patient care.

Considering direct patient care as a whole process, the staff viewed direct patient care slightly differently than the haemodialysis patients. The research has suggested that patients view direct patient care as the whole experience, and include lots of aspects in their definition of direct patient care, including clinical skills, chatting to staff and not being forgotten about. Conversely, staff view direct patient care

primarily as more clinically focused tasks and secondly the other related aspects to care, like cleaning and the stocking up of supplies.

As patients and staff consider direct patient care in different ways, the focus on direct patient care to be near the patient or beside the patient does not necessarily account for these patient perceptions. Whilst some of the research findings do support existing research on aspects of care, the conceptualisation of direct patient care being delivered by either active or passive care is a new way to describe how care can be delivered by both registered nurses and support workers.

Active care suggests that patients can feel cared for when they are being dealt with directly by staff, through engagement or as part of a clinical task. Passive care suggests that patients also feel cared for through the availability and visibility of staff. This passive care process can still allow patients to feel safe, individualised and comfortable through the staff's availability and visibility. Interestingly, patients can still feel passive care when a member of staff is visible but dealing with another patient. This demonstrates the difference between active and passive care.

Considering that, patients can feel cared for through both active and passive care, despite the potential lack of engagement between the staff member and the patient. The importance of the nurse and the support worker in the experience of direct patient care has been illustrated in the findings of this research. Patients value both the engagement with staff (active care) and the visibility and availability of staff (passive care).

Also, passive care allows the patient to feel secure and they value the expertise of the nurse/nurses who are responsible for them that day. The security allows the other aspects of the care routine to be carried out whilst there is no hands-on care occurring, but the nurse is occupied with administrative care and other tasks.

This research has a unique position within the current literature as it included both registered nurses and support workers, particularly considering the current health context where support staff will continue to supplement registered nurses and deliver patient care.

There is a value in the support workers, and the care they provide, however there is sometimes a distinction between the registered nurses and the support workers and their roles and duties. Patients did feel safe and cared for by the support workers, however the main focus from the patients was on the registered nurses who they viewed as in charge of their care.

The conceptual model in Figure 72 has illustrated the concept of direct patient care and the aspects which affect and make up this concept. The model has developed following the findings not aligning to the existing frameworks, although they are used as part of the development of the model.

8.2 Limitations

This ethnographic research was carried out by an insider researcher, who was also a registered nurse, to explore the care experienced in this setting.

The use of an insider as the researcher could be viewed as a limitation, due to their existing position and knowledge of the area. Through reflexive practice the researcher has demonstrated the awareness of their position, enabling the data to be considered trustworthy for others. The disregarding of member checking as part of the research process could also be viewed as a limitation of the research, however, the thick description of the field, with the interview data alongside to further support and contrast the views of participants does provide strength to the results of this research.

Data was validated by the support of the fieldnotes and the comparisons of the findings between the staff and patient interviews. Discussion of the findings and analysis with the supervisors also added a way of checking the data and analysis. Finally, the research was presented to the charge nurse, as a way of validation, after the research and analysis had been completed and writing up was underway.

A limitation of the research concerns observations and the restrictions put in place by the ethical committee. Due to every patient in a room requiring to have provided consent for observation to take place, this did mean that some rooms were unable to be observed. Keeping the setting and participants in their regular spaces and rooms

was an important aspect of the naturalistic enquiry and the movement of patients to other rooms may have impacted the research and data collected. Patient movement for the purposes of research would have been disruptive to their treatment experience. This movement may have impacted their experience and as the research has highlighted the value in patients being dialysed in their regular space around their regular group of patients, could have had negative consequences on the patients.

As patient participants required to be an existing out-patient who attended the unit, and not currently visiting as an in-patient, some potential situations and care experiences were also not able to be witnessed but some data on this particular aspect did come through from the interview data.

Despite getting permission to recruit adults with incapacity into the observation element of the research, no consent was gained from this small group of patients. This lack of inclusion in the research has not allowed the care they received to be considered but interview data from both staff and patient participants allowed for this group to be included from the responses although not directly focused on.

Whilst support workers were included in this research, when contrasted with the nurses, they were not necessarily the focus of patient care, but were identified to have very specific aspects to their role. The support workers who had more experience and were more established in the unit were considered differently to some of the newer or less experienced staff in providing aspects of care in the haemodialysis unit.

Crucial in the passive care aspect was the understanding that staff would come when patients needed them. If patients did call out, and staff did not attend or respond then this could have a different and potentially negative affect on care.

8.3 Implications for Practice, Policy and Education

The understanding that direct patient care is more than physical tasks in the haemodialysis unit can allow for practice changes and the importance of the combination of active and passive care within this setting suggests

Patients value both the interaction from the nursing staff and the engagement, connection and a perceived availability and visibility of the staff when they are within the haemodialysis unit.

This research has demonstrated that for patients, the perceived availability and visibility of the staff in the unit is of significant value to patients and their care experience in passive care.

Considering these findings, several aspects of healthcare practice, policy and education may require to be reconsidered in light of this research.

The connection between staff and patients experienced and highlighted in this research, in line with other studies, also requires to be highlighted for practice, policy and education. The connection has a significant impact on patients feeling cared for, and highlighting the ways in which a connection is experienced and established has a potential to improve patient care and experiences in healthcare settings.

Passive care as a finding demonstrates that patients have a huge value in the availability and visibility of staff to feel cared for. Despite not being directly engaged with or being close to staff, patients can still find this a positive aspect of patient care. Passive care is one way that care can be delivered, where a patient remains feeling cared for, despite staff not being actively engaged with that particular patient.

Whilst a lack of interaction between nursing staff and patients may suggest to an observer that there is no care or experience provided, this research has suggested a significant value in the nursing staff being present in the room despite the lack of attention or engagement. This combination of passive care alongside active care and the connection between the staff and the patient can all help patients to feel safe, comfort and individual.

This lack of direct engagement with patients should not be interpreted as staff 'doing nothing'; for passive care to occur, there must be an existing connection between the patient, the unit and staff in order for passive care to have a positive outcome for patient experience. This understanding of passive care does highlight there is some

value when staff are directly caring for patients and illustrates the complexities in the care delivery process.

Consideration of the environment and its impact on passive care also suggests that the location of the desk in the room where the patients are located is an important aspect of how passive care can be delivered. The visibility and availability of staff at all times while located in the haemodialysis room allows patients to feel safe as part of the care delivery process. The layout of healthcare settings requires consideration following this, as the staff being situated in the middle allows all patients to see the staff, even when they are not engaging directly with the patients. This set up with the patients' dialysis spaces being around the sides of the room allows the patients to see each other and what is going on, therefore they also see the staff and what they are doing.

Passive care does require to be carefully explained as a way of delivering care which is delivered in conjunction with active care. Patients value active care; however, they do not want to receive active care all the time. Patients place an importance on the nursing staff being available and visible and therefore cared for by staff, despite the lack of interaction and proximity, which conflicts with the original classification of direct patient care, which has been a focus as a way to improve healthcare and nursing practice within NHS Scotland.

Considering availability, adequate numbers require to be in place so patients can get assistance from nurses and support workers when required. The visibility of staff for patients may suggest that ward and clinical areas may require to be looked at in terms of layout, to facilitate staff being visible to patients.

There are potential implications for staffing levels and nurses' practice awareness following the findings of this research. There is strong evidence to support the importance of the visibility of staff to the patient experience, which can subsequently help patients feel safe and secure. This could suggest that current health policy and practice, where single room hospitals are becoming the main way of in-patient care, could present challenges in supporting patients in their safe and secure environment, due to potential lack of visibility brought about by the single room.

Considering the use of the term direct patient care, and the use of Releasing time to care, the research here has highlighted that direct patient care in this context is more than spending time together between a staff member and a patient. The research here has suggested that direct patient care is actually more than being close.

Despite the lack of engagement between the staff and the patient as defined by passive care between two – nursing staff and patient, this aspect can still be part of providing care and does not necessarily align with the work and activity follow descriptions.

This active and passive care is not something that can be measured as quantitative data through the run chart. The impact of the relationships and environment allow for care to be experienced throughout a patient's time on dialysis, through what has been described here as active and passive care.

8.4 Future research

Following this research and its identified findings, several further research projects could be carried out to further explore the findings in relation to healthcare and nursing practice.

Further exploration using this research design should be carried out in other healthcare settings, including other types of wards and environments, to see if there are similar appreciations for the passive care in other contexts. The value identified in the process described here in passive care requires further exploration, within the haemodialysis context and other healthcare settings. The individual connection identified within this research could be further explored, to identify how this connection is established, particularly for new patients and considering other contexts and clinical environments. There is also a potential for further research to test the model identified from the findings of this research and the relationships between the concepts within it.

Currently within healthcare, there is a high value from stakeholders for new hospitals and healthcare settings undergoing redesign for patient spaces to be made as single rooms, rather than patients sharing rooms or areas when requiring care or treatment

particularly as an in-patient. The findings from this research suggest that the value of the staff being visible and available to patients is important to the care experience, and potentially the single rooms would not facilitate for passive care, due to the patient being behind a door, and away from the staff, when they are not being directly cared for.

The value of passive care highlighted through this ethnographic work is that the visibility and availability of the staff, mainly registered nurses in this research, is hugely important and adds to the direct care experience for the patients in this large haemodialysis unit.

Relationships or connections are developed through the delivery of both active and passive care, where time together and also patients witnessing staff working with others helps establish a connection viewed as important in this healthcare context.

Particularly within haemodialysis, there is an encouragement to the practice of 'self-care' where patients are carrying out their treatment almost independently with little input from staff, whether registered nurse or support worker, despite being in a hospital environment. This self-care practice is allowing patients to lead and have more control over their treatment. The lack of nursing care for these haemodialysis patients is viewed as valuable in this study and should be further explored in order to understand the nurses' caring role within this new developing haemodialysis context.

Patients who carry out home haemodialysis, where the dialysis machine is located within their home and have very minimal staff support due to this, have a potentially different caring experience from the patients receiving in-hospital haemodialysis. Staff are not available or visible physically in the patients' own homes. One way to further consider care is to focus specifically on new patients within haemodialysis, or the self-caring patients, to explore their understandings of care in this context and what they view as valuable in their care experience.

The support worker position, whilst included in the research as a participant group, was not directly differentiated by patients. There is little literature on the role of the support worker in different aspects of care and presence, as registered nurses are

usually the focus in research on this aspect. The support worker position and importance in relation to direct care could be further explored, particularly focusing on clinical support workers in this context and others.

The research here has begun to include this role and how healthcare support workers can impact and deliver direct patient care, and have a fundamental position within the care provided. Future research should further explore this role and the importance of this position in care for patients in this context and others.

In the current clinical and policy context, considering the changing roles and new roles of associate nurses, change could continue to occur and impact the direct care and the patients' feelings around care and care provision in clinical settings.

Healthcare and nursing roles remain to develop in healthcare settings. Within the haemodialysis unit, where this research took place, there is a move to the development of new, advancing practice roles and also the further training of the support worker staff to more clinical roles and tasks. Further research is suggested to continue to explore care delivery with these changing roles to explore these new roles and how this affects patient experience and care delivery.

Considering nursing and nursing work in the haemodialysis unit and the importance of care through both these means adds further value to Polaschek's work (2003) and their model for nursing work in a renal setting. The term used in this research is negotiated care and the support of patients to negotiate the treatment and regime, however this model does not highlight the non-engaged element of nursing practice within a haemodialysis unit, shown in this research to provide support and value to the patient experience.

This PhD study has provided the opportunity to explore the concept of direct patient care and what that is within the unique environment of a haemodialysis unit considering both registered nurses and support workers who are key in providing this direct patient care.

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Appendix 1: Direct Care Time as a measure

Measure	Why is it important?	Operational Definition	Data Source
Direct Care Time	The more time that is available for direct patient care, the more likely it is that the quality of care will improve or remain at a high standard	1st Assessment: 12hr observation of one trained nurse between 6am and 6pm on a weekday not featuring a ward round. 2nd to 6th assessment: monthly featuring 8hrs 7am to 3pm. Ongoing assessments: Quarterly 8hr. Weekday to remain constant. (Count of direct care time minutes over the time period/total minutes in assessment period)*100. Ideally to feature the same nurse	Ward

Who is the measure intended for?	Who collects?	Frequency?	Suggested Trend	How do I use this measure? (Tools available on the NHS Institute Productive Ward pages)	Reported as
Ward leader, matron, ward staff	Ward leader	Monthly moving to quarterly	Initially UP then stabilise	Input the results from the Activity Follow sheets into the Totaliser Tool and print out the latest chart	% direct care

Direct Patient Care as a Measure

Reproduced from The Productive Ward: Releasing Time to Care Knowing How we are Doing Module (Version 2) NHS Institute for Innovation and Improvement (2008)

Appendix 2: Direct Patient Contact or Direct Care Description Examples

Activity Follow v6

Direct Care (At patient bed or nr patient)	A	Ward Round			
	B	Medicine Round			
	C	Toileting			
	D	Meal Round			
	E	Nutritional Management			
	F	Mobilising			
	G	Observations			
	H	Assessments			
	I	Nursing Procedure			
	J	Hygiene			
	K	Bed Making			
	L	Social Care			
	M	Patient Communication			
	N	Relative liaison			

NHS Scotland RTC Mental Health Ward Activity Follow Descriptors

Direct Care (At patient bed or nr patient)	A	Constant observations	
	B	Special Observations	
	C	Routine hrly checks	
	D	Therapeutic Int (ind)	
	E	Therapeutic Int (group)	
	F	MDT meeting WTP	
	G	Medicine round	
	H	toileting	
	I	Mealtime	
	J	Meal assistance	
	K	mobilising	
	L	Physical observations	
	M	admission process - WTP	
	N	Discharge Process -WTP	
	O	Nursing Procedures	
	P	Patient Hygiene	
	Q	Care planning WTP	
	s	Patient Communication	
	T	Relative Liaison	
	U	Patient emerg. intervention	
	V	Other	

Perceptions and Experiences of Direct Patient Care

Direct Care (At patient bed or nr patient)	A	Ward Round			
	B	Medicine Round			
	C	Breast Feeding			
	D	Meal Round			
	E	Baby care			
	F	Mobilising			
	G	Obs Mother and Baby			
	H	Assessments			
	I	Midwifery Procedure			
	J	Hygiene- mother only			
	K	Bed Making			
	L	Social Care			
	M	Relative liaison			

Productive Ward- Activity Follow Midwifery v5

Direct Care/Risk observations (At patient bed or nr patient)	A	Constant obs		
	B	Intermitted Obs		
	C	General Area Obs		
	D	Patient check in		
	E	Psychological support		
	F	Diversional therapy		
	G	Ward Round WTP		
	H	Medicine Round		
	I	Toileting		
	J	Meal Round		
	K	Nutritional Management		
	L	Mobilising		
	M	physical observations		
	N	Assessments		
	O	Nursing Procedure		
	P	Hygiene		
	Q	Bed Making		
	R	Care planning WTP		
	S	Patient Communication		
	T	Relative liaison		

Activity Follow Sheet MH secure unit

Direct Care (At patient bed or nr patient)	A	Ward Round	
	B	Medicine Round	
	C	Breast Feeding	
	D	Meal Round	
	E	Baby Care	
	F	Mobilising	
	G	Obs mother & baby	
	H	Assessments	
	I	Midwifery Procedure	
	J	Hygiene mother only	
	K	Bed Making	
	L	Social Care	
	M	Relative liaison	
	N	Patient Communication	
	O	Other	

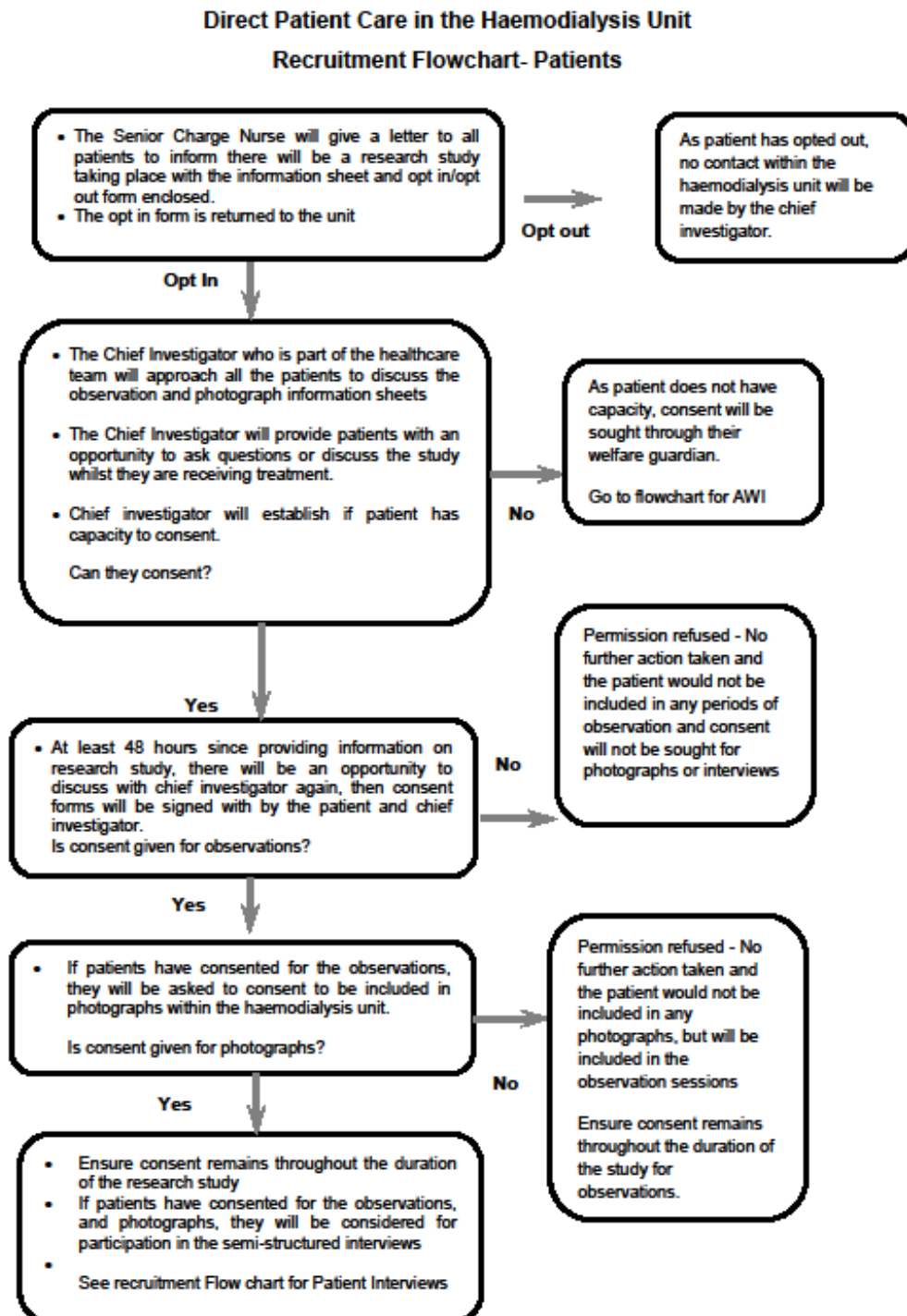
Productive Ward- Activity Follow Maternity V7

Appendix 3: Activity Description Example

List of the activities with a brief description Productive Ward: Releasing time to Care programme for a Community Hospital.

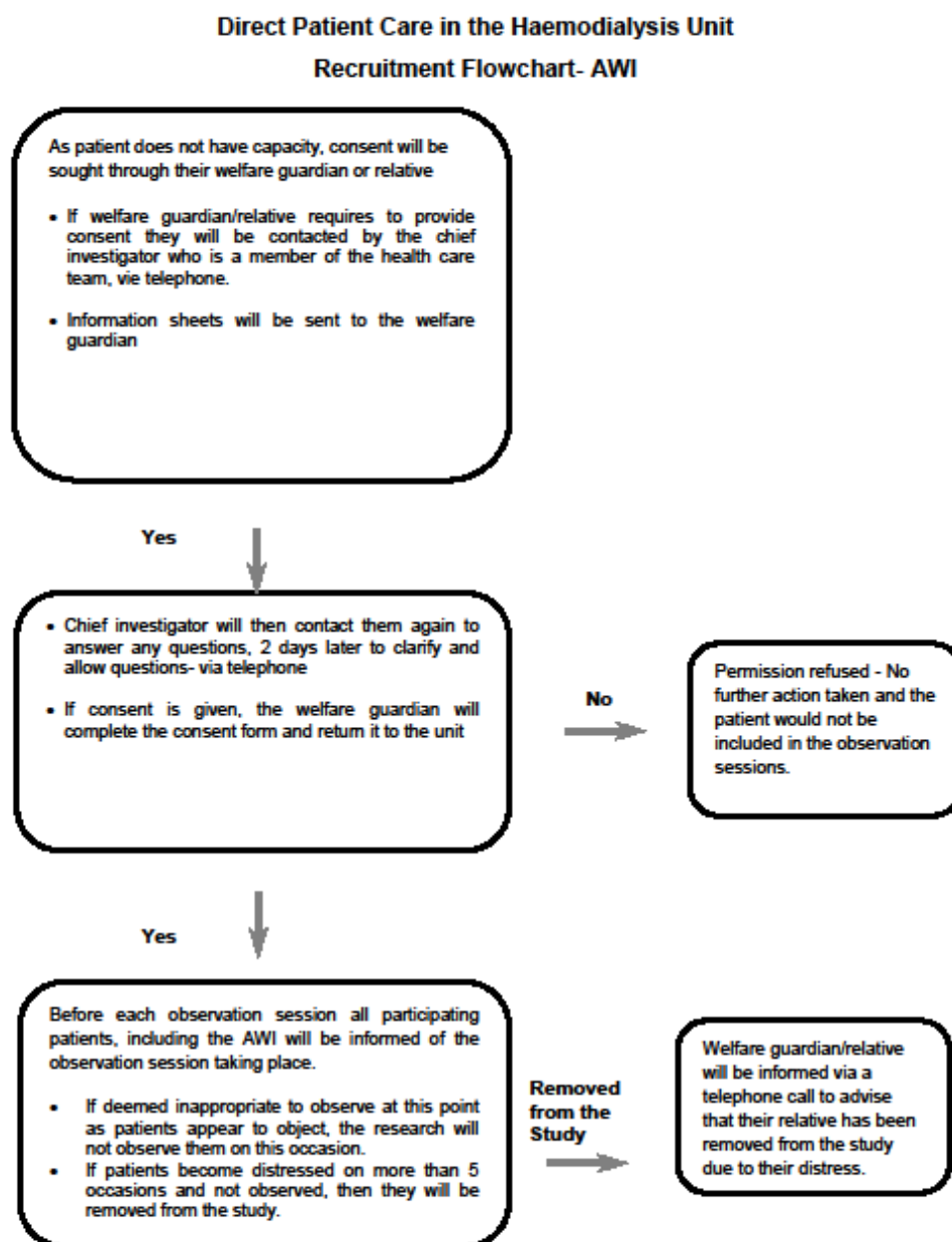
Activity	Description
Direct Patient Contact	This is time spent with a patient or several patients at once. Including ward rounds and handovers done in the presence of the patient. Drug administration to patient.
Clinical Meeting	Meetings where patients or any clinical issues are discussed. Would include ward rounds and handovers not in the presence of patients.
Clinical Administration	Reviewing, completing and updating patient and clinical documentation. Preparing for drug administration.
General Administration	Such as ordering supplies, photocopying, doing the off duty and other such tasks.
Non Clinical meeting	Staff meetings including staff appraisals etc, and management meetings such as finance meetings.
Telephone contact	All time spent on the telephone in the course of your work.
CPD/ give or receive training	Any training courses or teaching sessions - either attending or giving them.
Relative/Carer Contact	Any time spent discussing a patient with their relatives or friends.
Clinical/medical audit	Any time spent looking at information or supplying information for auditing purposes.
Breaks	Time spent on formal breaks such as morning coffee, afternoon tea and lunch.
Actively waiting for patient	Waiting to do something for a patient, such as waiting for another professional to finish with the patient or waiting for them to come back from another department.
Looking for/collecting	Looking for supplies/equipment, collecting a patient, collecting supplies/equipment.

Appendix 4: Initial Recruitment Flow Chart - Patient Participants



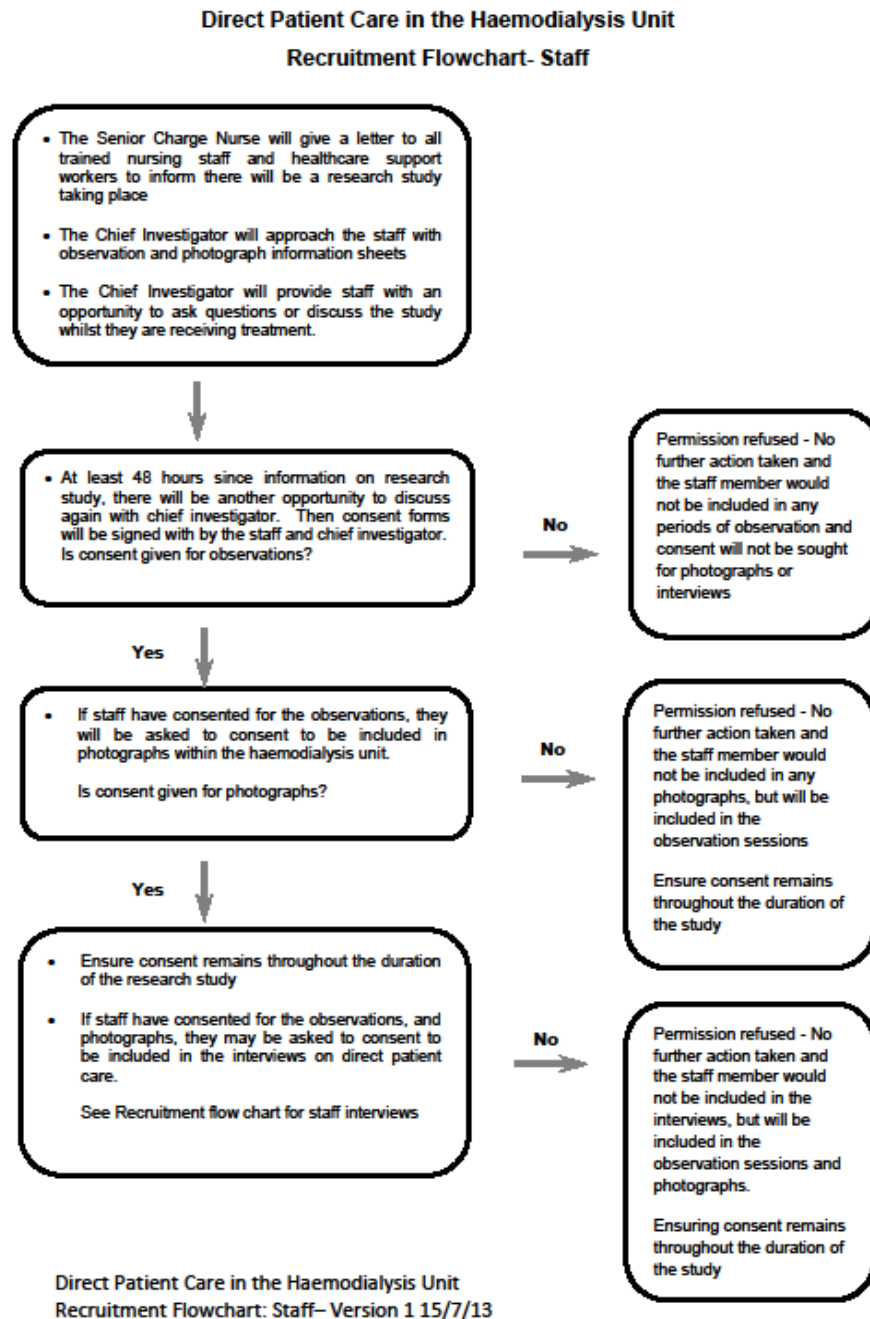
Direct Patient Care in the Haemodialysis unit
Recruitment Flowchart: Patients- Version 3 24/10/13

Appendix 5: Initial Recruitment Flow Chart - AWI Participants

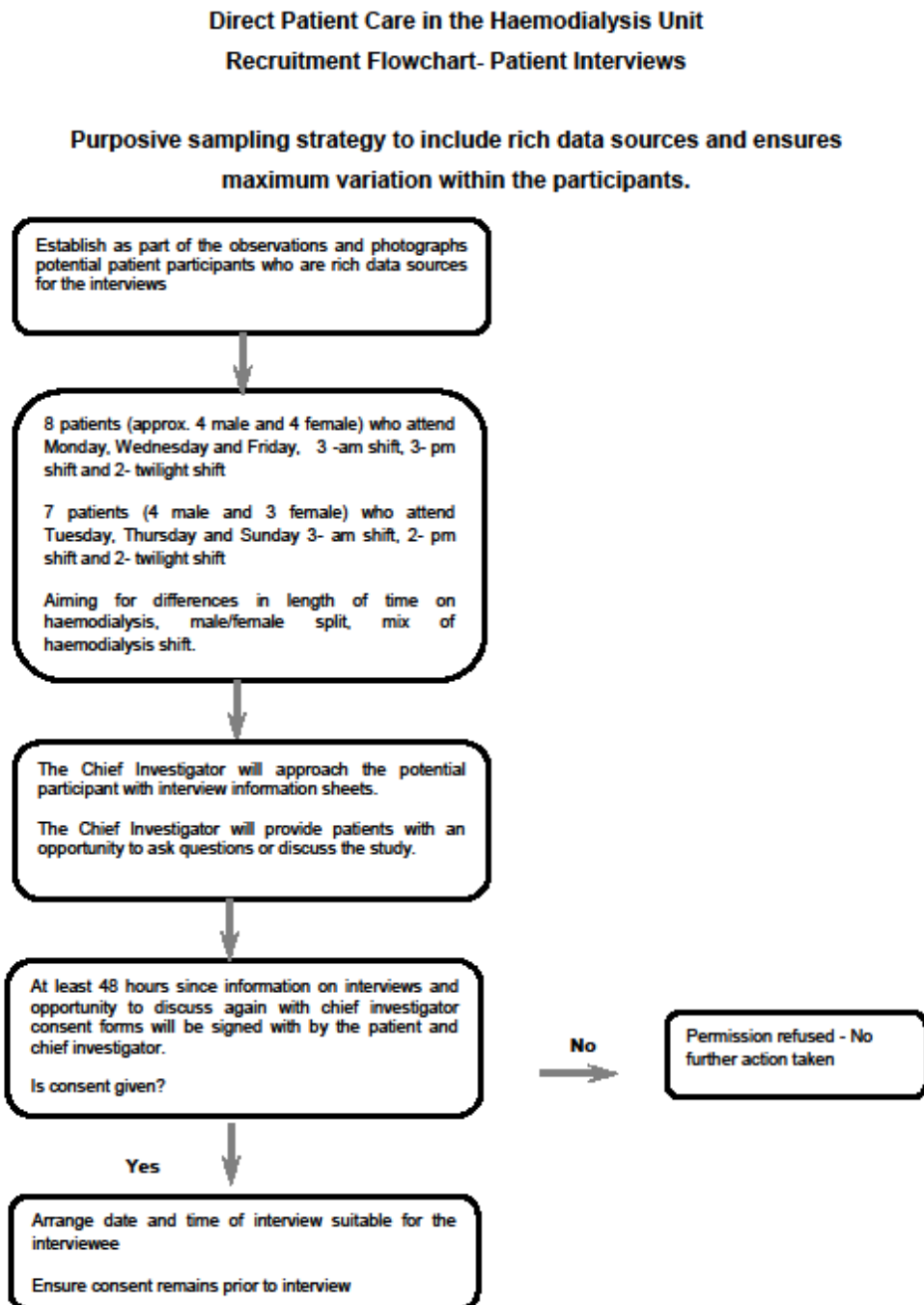


Direct Patient Care in the Haemodialysis unit
Recruitment Flowchart: AWI- Version 2 11/9/13

Appendix 6: Initial Recruitment Flow Chart - Staff Participants

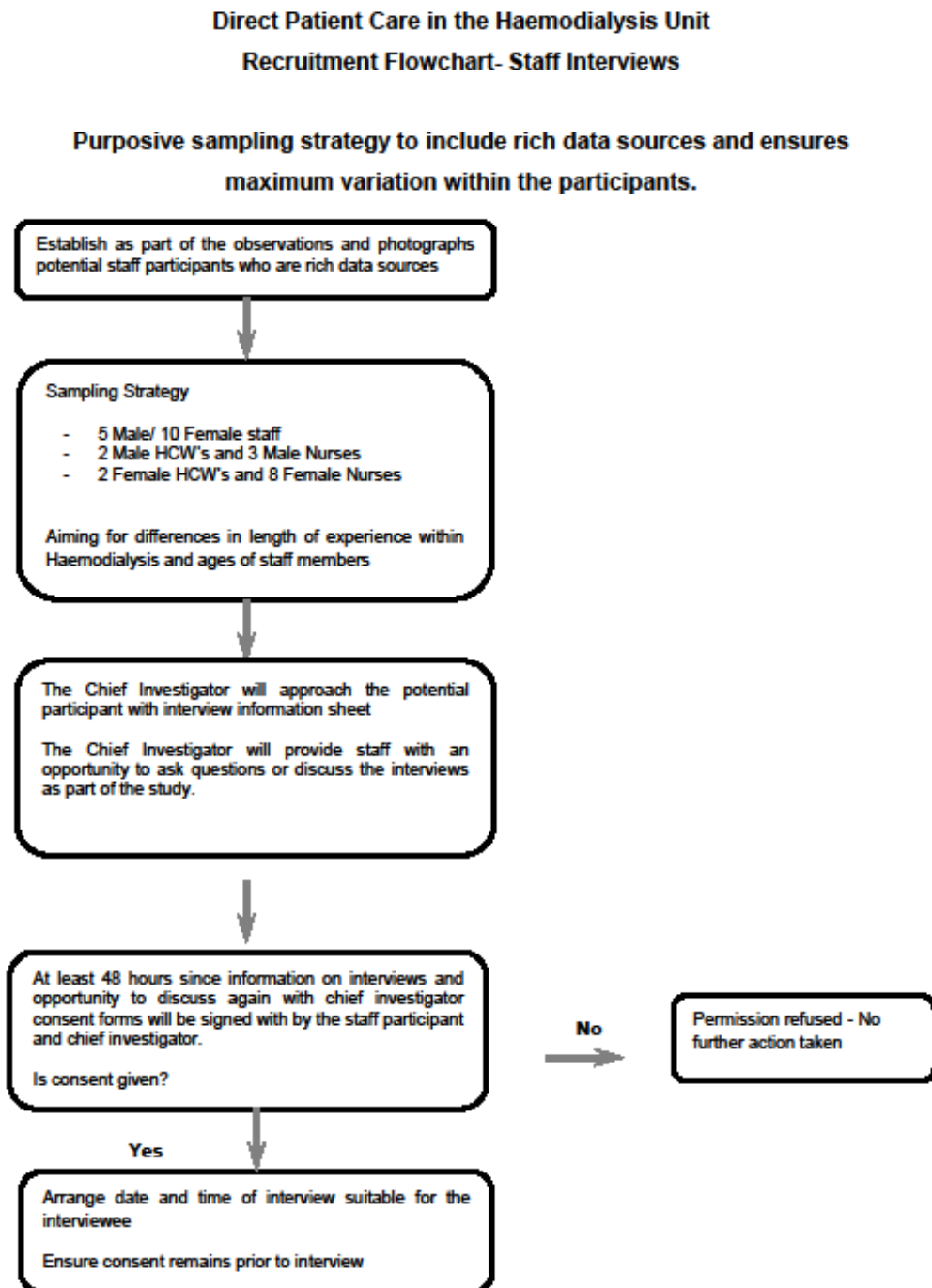


Appendix 7: Interview Recruitment Flowchart - Patient Participants



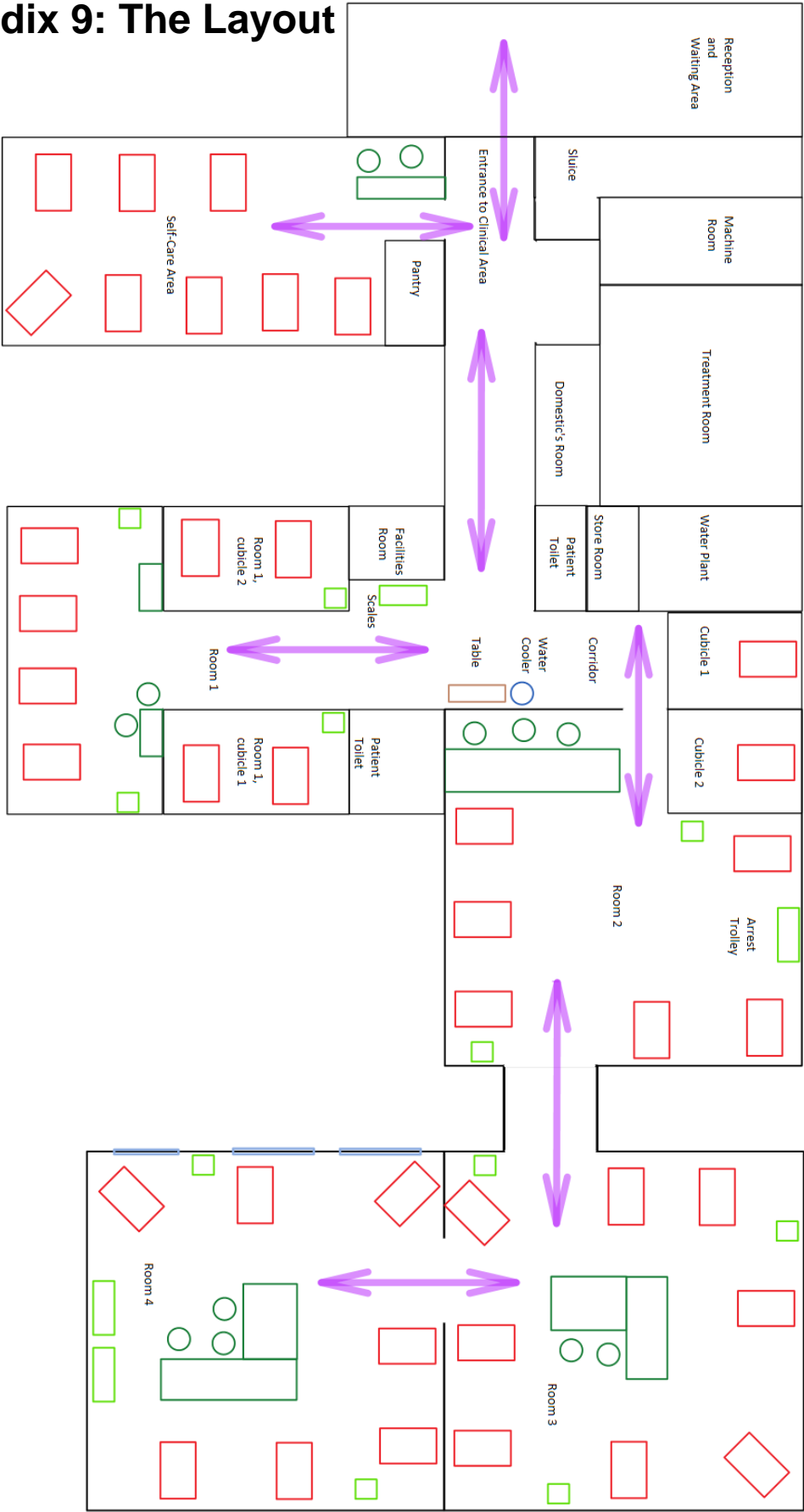
Direct Patient Care in the Haemodialysis Unit
Recruitment Flowchart: Patient Interviews– Version 1 15/7/13

Appendix 8: Interview Recruitment Flow Chart – Staff Participants



Direct Patient Care in the Haemodialysis Unit
Recruitment Flowchart: Staff Interviews– Version 1 15/7/13

Appendix 9: The Layout



Appendix 10: Topic Guide for Interviews

Questions for Patient Participants

What do you think direct patient care is in the haemodialysis unit?

Have you heard of the term direct patient care?

Can you tell me about the direct care you have received in the unit?

Who provides this direct care?

What do you view as important when you are in the haemodialysis unit?

Questions for Staff Participants

What do you think direct patient care is in the haemodialysis unit?

Have you heard of the term direct patient care?

What do you view as important direct patient care to provide in the haemodialysis unit?

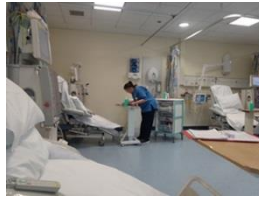
What can a nurse provide as direct care for patients?

What can a support worker provide as direct care for patients?

Appendix 11: Thumbnail Photographs



001



002 (Figure 37)



003



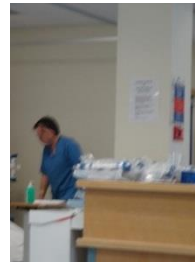
004



005 (Figure 56)



006



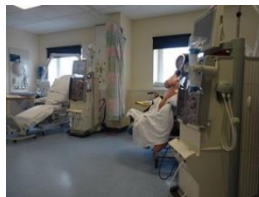
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013 (Figure 51)



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016 (Figure 49)



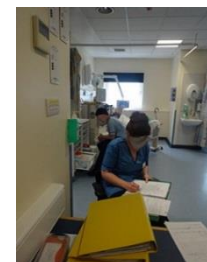
017



018 (Figure 64)



019 (Figure 59)



020 (Figure 61)

Perceptions and Experiences of Direct Patient Care



021



022 (Figure 14)



023 (Figure 57)



024



025



026



027 (Figure 54)



028



029 (Figure 60)



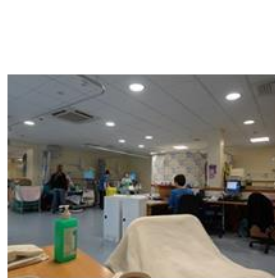
030 (Figure 26)



031 (Figure 43)



032 (Figure 30)



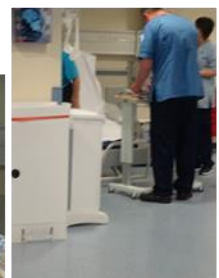
033 (Figure 37)



034 (Figure 35)



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040 (Figure 18)

Perceptions and Experiences of Direct Patient Care



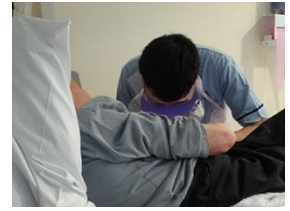
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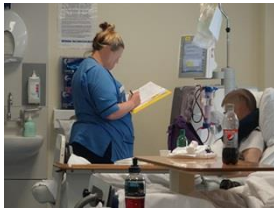
042 (Figure 36)



043



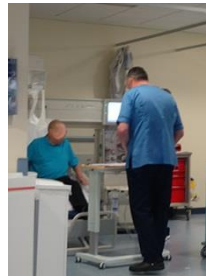
044 (Figure 27)



045



046



047 (Figure 42)



048



049



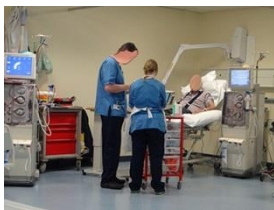
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051



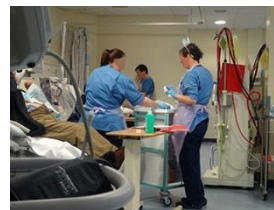
052 (Figure 17)



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054



055



056 (Figure 68)



057



058 (Figure 31)



059

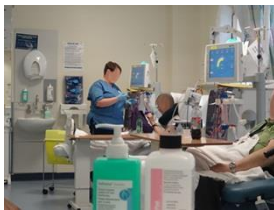


060

Perceptions and Experiences of Direct Patient Care



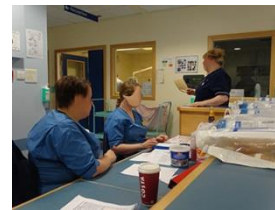
061 (Figure 15)



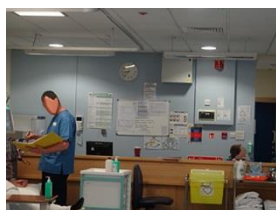
062 (Figure 41)



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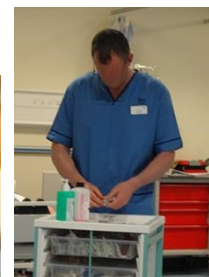
065 (Figure 19)



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067 (Figure 16)



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071 (Figure 53)



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073 (Figure 33)



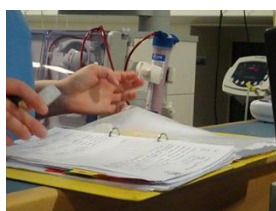
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077 (Figure 29)



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079 (Figure 65)



080 (Figure 22)

Perceptions and Experiences of Direct Patient Care



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083 (Figure 45)



084 (Figure 58)



085 (Figure 32)



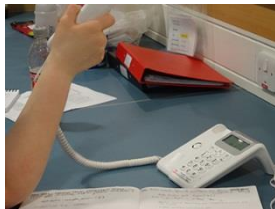
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087 (Figure 28)



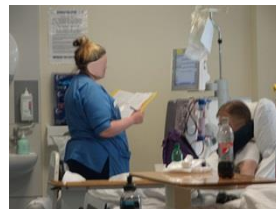
088 (Figure 46)



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090 (Figure 40)



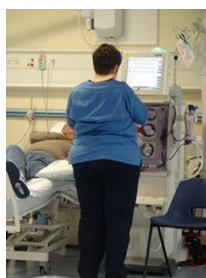
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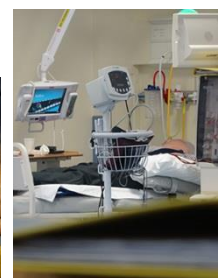
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094 (Figure 54)



095 (Figure 23)



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097 (Figure 24)



098 (Figure 66)



099 (Figure 38)



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Perceptions and Experiences of Direct Patient Care



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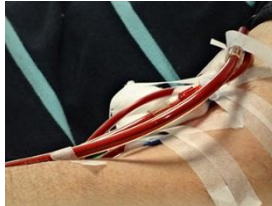
103



104 (Figure 44)



105 (Figure 50)



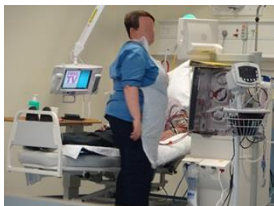
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109 (Figure 34)



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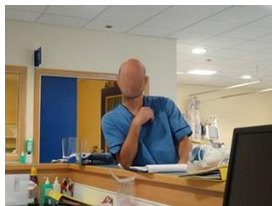
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114 (Figure 25)



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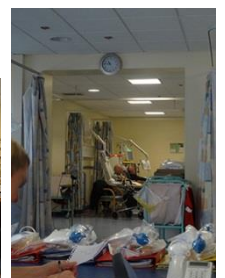
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119 (Figure 63)



120 (Figure 20)

Perceptions and Experiences of Direct Patient Care



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122 (Figure 62)



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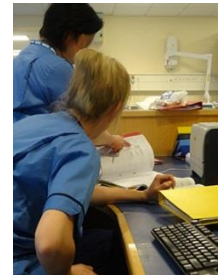
125 (Figure 55)



126 (Figure 67)



127 (Figure 39)



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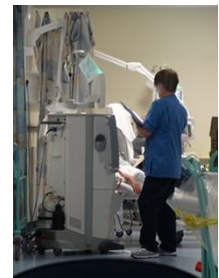
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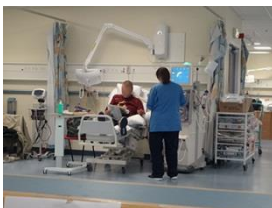
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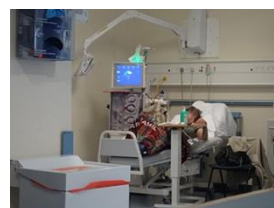
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Perceptions and Experiences of Direct Patient Care



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Perceptions and Experiences of Direct Patient Care



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163 (Figure 12)



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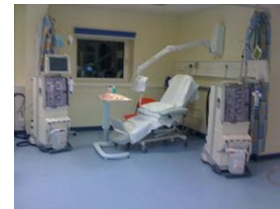
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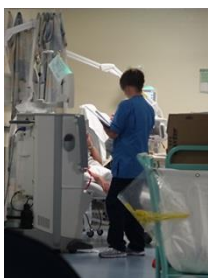
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182 (Figure 10)



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184 (Figure 13)



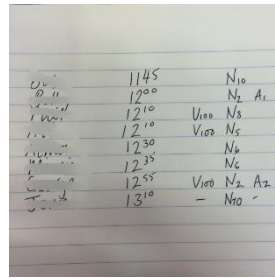
185 (Figure 11)



186 (Figure 09)



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188 (Figure 21)

Appendix 12: Provisional Ethical Approval

**Scotland A Research Ethics
Committee**

Research Ethics Service
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk



Miss Alison Wood
Nursing Studies, School of Health in
Social Science
The University of Edinburgh
The Medical School
Teviot Place
Edinburgh
EH8 9AG

Date: 1 October 2013
Your Ref.:
Our Ref.: 13/SS/0163
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Miss Wood

Study title: Direct patient care in the haemodialysis unit
REC reference: 13/SS/0163
IRAS project ID: 130235

The Scotland A Research Ethics Committee reviewed the above application at the meeting held on 26 September 2013. Thank you for attending to discuss the application.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
REC application: IRAS Form	3.5	11 September 2013
Protocol	2	05 September 2013
Investigator CV		10 September 2013
Participant Information Sheet: Participant: Observation	2	05 September 2013
Participant Consent Form: Participant: Observation	2	05 September 2013
Participant Consent Form: Participant: Photograph	2	05 September 2013
Participant Information Sheet: Welfare Guardian/Nearest Relative	2	05 September 2013
Participant Consent Form: Welfare Guardian/Nearest Relative	2	05 September 2013
Participant Information Sheet: Staff: Observation	2	05 September 2013
Participant Consent Form: Staff: Observation	2	05 September 2013
Participant Consent Form: Staff: Photograph	2	05 September 2013
Participant Information Sheet: Participant: Interview	2	05 September 2013
Participant Consent Form: Participant: Interview	2	05 September 2013

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Participant Information Sheet: Staff: Interview	2	05 September 2013
Participant Consent Form: Staff: Interview	2	05 September 2013
Letter of invitation: Participant	2	05 September 2013
Letter of invitation: Staff	2	05 September 2013
GP Letter	2	05 September 2013
Flowchart: Participants Observation	2	11 September 2013
Flowchart: Participants-AWI Observation	2	11 September 2013
Flowchart: Staff Observation	1	15 July 2013
Flowchart: Participant Interview	1	15 July 2013
Flowchart: Staff Interview	1	11 September 2013

Provisional opinion

The Committee noted this was a qualitative study using an ethnographic study design. This involved largely observing patients and staff to gain a better understanding of the direct care provided to patients in the Haemodialysis Unit. The Committee considered whether justification had been provided to include adults who lacked capacity and whether the study could be undertaken on only those participants who could give consent. The Committee recognised that adults who lacked capacity were an integral part of the Unit and given the observational nature of the study could present problems. This could also equally apply to patients who could give consent and decide not to take part in the study. The Committee further noted that this was a student study for a PhD and that the applicant who was the chief investigator worked in the Unit where she intended to undertake the study. While the data protection arrangements for the study appeared satisfactory the application indicated that although the aim was to anonymise the information collected there was an acceptance that this may not always be feasible. The Committee wondered how generalisable the findings of the study would be and whether what was planned was more appropriately service development than research. The Committee considered the recruitment process and felt there was the potential for coercion given the number of times the chief investigator was planning to approach patients and staff. They considered that the charge nurse should as part of the invitation send out the information sheet and consent form to potential participants and staff and ask them to return the signed consent form to the chief investigator. The Committee noted some contradictions in the information sheet which should be addressed.

Miss Wood and Dr Rogers attended to discuss the study. Miss Wood was asked how the study findings would benefit the performance of the Unit. In response Miss Wood mentioned that the research was looking at how the Unit functioned in terms of care



provided from the perspective of patients and staff and subsequently how direct care could be improved. In defining direct care Miss Wood explained the aim was to see if there was an opportunity for staff to spend more time with patients in interactions such as conversation. On being asked how she would record the multiple interactions that would take place Miss Wood indicated that she was planning for the study to run for nine months which would initially give her the opportunity to generally observe what was going on within the Unit. Further down the planned timetable the intention was to focus on areas which were of more interest to her. When asked about the study outcome Miss Wood mentioned the research would give her a more solid understanding of what patients would like and what nurses and care staff were looking for to improve direct care in the Unit. On being asked about the advantages and disadvantages of doing the research in her Unit Miss Wood said she had already built up a relationship with the patients but when she was doing her research she would very much be a researcher. In relation to disadvantages she did not see any but pointed out that in the event of any emergency that arises she would revert to her nursing role if required. Miss Wood was asked if the outcome from her study could be adapted to Units elsewhere. She thought this was unlikely as the results would be specific to her own Unit but there was the feasibility that elements from her study outcome could be applied elsewhere. The Committee asked Miss Woods about previous research projects in this field. Miss Woods confirmed there had been but would not be using any of the findings as her study was looking specifically looking at direct care. The Committee raised with Miss Wood about recruitment approach to potential participants and the number of approaches she was planning to make. The Committee considered it would be better for the Charge Nurse as part of the invitation process to hand out the information sheet and consent forms which could then be returned to her if consent was obtained. The Committee had also noted that Miss Wood was planning to access medical records but when asked about this she indicated that that was an error in the application. Miss Wood was asked how her colleagues in the Unit would react to her study. She explained that they had been very supportive of the study. In response to being asked about the research element Miss Wood said the research objective of the study was to establish if the reality of the understanding from patients and staff of the expectation of the Unit expectations were being met. On being asked about the mechanism for dealing with patients and staff who decline to participate Miss Wood confirmed they would not be observed but from her nursing perspective she would continue to maintain a relationship with patients. Miss also confirmed there would be structural changes following the completion of the study. Miss Wood was asked about the inclusion of adults lacking capacity. In response Dr Rogers said that patients who lacked capacity were an integral part of the Unit and that she had been persuaded, as the academic supervisor, of the value of their inclusion in the study.



After Miss Wood and Dr Rogers left the meeting the Committee discussed whether this application was research or service evaluation. On balance they accepted there was a research element to the study. They also accepted that the inclusion of adults lacking capacity had been justified by Dr Roger's comments.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

1. The application should tabulate a hypothesis outcome to demonstrate how the study would improve the direct care of adults lacking capacity.
2. The initial approach letter from the charge nurse should be more invitational, emphasising that there was no obligation to take part, including with it the information sheet and a tear-off slip to be returned with either agreement to the researcher approaching them to explain the study and obtain consent and an opt out option.
3. The application should give some indication what if any generalisable knowledge was likely to be gained from the study.
4. The information sheets should be proof read to correct grammatical errors and contradictions.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Dr Alex Bailey (telephone 0131 465 5680).

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the



date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 31 October 2013.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 13/SS/0163-Please quote this number on all correspondence

Yours sincerely

A handwritten signature in black ink, appearing to read 'Ian Zealley', written over a light blue horizontal line.

Dr Ian Zealley
Committee Chairman

cc: Ms Marianne Laird
Mrs Karen Maitland, NHS Lothian R&D department

Scotland A REC

Attendance at Committee meeting on 26 September 2013

Committee Members:

Name	Profession	Present	Notes
Dr Fiona C Denison	Senior Lecturer and Honorary Consultant in Maternal and Fetal Health	Yes	
Dr Bridget Harris	Clinical Research Specialist	No	
Mrs Fiona Mack	Clinical Pharmacist	Yes	
Dr Mary Macleod	Clinical Pharmacologist-Consultant Physician	Yes	
Mrs Katherine McGuigan	Nurse	No	
Canon Matt McManus	Parish Priest	Yes	
Dr Craig Melville	Senior Lecturer in Learning Disabilities Psychiatry	No	
Dr Zoe Morrison	Research Fellow, Centre for Population Health Sciences	No	
Mrs Wendy Nganasurian	Retired	Yes	
Dr Anthony Pottage	retired Physician/Clinical Pharmacologist	Yes	
Dr Richard Quigley	General Practitioner	Yes	
Dr Colin Selby	Consultant Physician	Yes	
Dr Rachel Smith	MRC Programme Manager (Training and Partnerships)	Yes	



Mrs Mary Sweetland	Statistician	Yes	
Mrs Margaret Thomson	Retired	Yes	
Professor Nigel Webster	Chair of Anaesthesia & Intensive Care	No	
Dr Ian Zealley	Consultant	Yes	

Also in attendance:

Name	Position (or reason for attending)
Dr Alex Bailey	Scientific Officer
Mr Walter Hunter	Committee Coordinator

Written comments received from:

Name	Position
Dr Craig Melville	Senior Lecturer in Learning Disabilities Psychiatry

Appendix 13: Acknowledgement of Compliance

**Scotland A Research Ethics
Committee**

Research Ethics Service
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk



Miss Alison Wood
Nursing Studies, School of Health in
Social Science
The University of Edinburgh
The Medical School
Teviot Place
Edinburgh
EH8 9AG

Date: 28 October 2013
Your Ref.:
Our Ref.: 13/SS/0163
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Miss Wood

Study title: Direct patient care in the haemodialysis unit
REC reference: 13/SS/0163
IRAS project ID: 130235

Thank you for your e-mail dated 28 October 2013. I can confirm the Scotland A REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 18 October 2013

Documents received

The documents received were as follows:

Document	Version	Date
GP/Consultant Information Sheets	3	24 October 2013
Letter of invitation to participant: Participant	4	24 October 2013
Recruitment Flowchart: Participant: Interviews	1	15 July 2013
Recruitment Flowchart: Staff	1	15 July 2013
Recruitment Flowcharts: Staff: Interviews	1	15 July 2013
Recruitment Flowchart: AWI	2	11 September 2013
Letter of Invitation: Staff	4	24 October 2013
Participant Consent Form: Participant: Observations	4	24 October 2013
Participant Consent Form: Participant: Photographs	4	24 October 2013
Participant Consent Form: Welfare Guardian/Nearest Relative	4	24 October 2013
Participant Consent Form: Staff: Observations	4	24 October 2013
Participant Consent Form: Participant: Interviews	4	24 October 2013

Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby

Participant Consent Form: Staff: Interviews	4	24 October 2013
Participant Consent Form: Staff: Observations	4	24 October 2013
Participant Consent Form: Staff: Photographs	4	24 October 2013
Participant Consent Form: Participant: Opt in/Opt out	1	05 October 2013
Participant Information Sheet: Participant	4	24 October 2013
Participant Information Sheet: Welfare Guardian/Nearest Relative	4	24 October 2013
Participant Information Sheet: Staff	4	24 October 2013
Participant Information Sheet: Participant: Interviews	4	24 October 2013
Participant Information Sheet: Staff: Interviews	4	24 October 2013
Protocol	3	24 October 2013
Participant: Recruitment Flowchart	3	24 October 2013

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC application: IRAS Form	3.5	11 September 2013
Investigator CV		10 September 2013
Covering Letter		15 October 2013
Patient Opt-in/Opt-out form	1.0	05 October 2013
Response to Request for Further Information		15 October 2013
Protocol	3	24 October 2013
Participant Information Sheet: Participant	4	24 October 2013
Participant Information Sheet: Welfare Guardian/Nearest Relative	4	24 October 2013
Participant Information Sheet: Staff	4	24 October 2013
Participant Consent Form: Participant: Observations	4	24 October 2013
Participant Consent Form: Participant: Photographs	4	24 October 2013
Participant Consent Form: Welfare Guardian/Nearest Relative	4	24 October 2013
Participant Consent Form: Staff: Observations	4	24 October 2013
Letter of invitation to participant:	4	24 October 2013
GP/Consultant Information Sheets	3	24 October 2013
Participant: Recruitment Flowchart	3	24 October 2013

Recruitment Flowchart: Participant: Interviews	1	15 July 2013
Recruitment Flowchart: Staff	1	15 July 2013
Recruitment Flowcharts: Staff: Interviews	1	15 July 2013
Recruitment Flowchart: AWI	2	11 September 2013
Letter of Invitation: Staff	4	24 October 2013
Participant Information Sheet: Participant: Interviews	4	24 October 2013
Participant Information Sheet: Staff: Interviews	4	24 October 2013
Participant Consent Form: Participant: Interviews	4	24 October 2013
Participant Consent Form: Staff: Interviews	4	24 October 2013
Participant Consent Form: Staff: Observations	4	24 October 2013
Participant Consent Form: Staff: Photographs	4	24 October 2013
Participant Consent Form: Participant: Opt in/Opt out	1	05 October 2013

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

REC reference number: 13/SS/0163-Please quote this number on all correspondence

Yours sincerely



WALTER HUNTER
Committee Co-ordinator

cc: Ms Marianne Laird

Mrs Karen Maitland, NHS Lothian R&D department

Appendix 14: Patient Opt in/Out Letter

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/GE device),
Patient Opt-in/Opt-out form V1 date [05/10/13]



Participant Opt-in/Opt-out Form Direct Patient Care in the Haemodialysis Unit

Please complete this form and return it in the envelope provided to the Haemodialysis Unit.

Name of Potential Participant

Date

Please initial appropriate box

1. I am interested in learning more about this study.
Please approach me regarding this study.

☐

2. I am NOT interested in this study. Please do not approach
me again about this study.

☐

Appendix 15: Patient Introductory Letter

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Patient Introductory Letter V4 date [24/10/13]



Dear

Direct Patient Care in the Haemodialysis Unit

I am writing to inform you of a research study taking place in the haemodialysis unit you attend for treatment, and would like to invite you to participate in this project.

The purpose of the study is to explore the direct patient care which occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The study will explore what happens in the unit for staff and for patients.

The research will particularly focus upon these everyday caring activities and establish what direct care is within this setting and seek to understand what patients and staff think about direct care within haemodialysis. Information will be collected through observing what occurs, photographs and also some interviews.

There is no obligation for you to take part in the study, and you should talk to others about participating in the project before you decide if you want to take part.

It is important to know that this letter is not to tell you to join this study. It is your decision. Your participation is voluntary. Whether or not you participate in this study will have no effect on your relationship with NHS Lothian and the haemodialysis unit as a patient.

1. If you would like to learn more about this study, please check box #1 on the enclosed form and return to the haemodialysis unit.
2. If you do not wish to hear about this study and do not wish to be contacted again about this study, please check box #2 on the enclosed form and return to the haemodialysis unit.

The information sheet relating to the study is enclosed with this letter. Please take the time to read it carefully.

If you would like to talk to someone directly, Alison Wood, the chief investigator for the project will be within the haemodialysis unit. Alison is a staff nurse and a member of the staff in the haemodialysis unit. The research project is part of a PhD at the School of Health In Social Science, at the University of Edinburgh.

Perceptions and Experiences of Direct Patient Care

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Patient Introductory Letter V4 date [24/10/13]



If you or your family have any queries about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131) 242-1201, or direct questions to her directly when you see her in the unit.

There will be copies of the letter available in the haemodialysis unit if you require another.

Thank you for your time and consideration.

Yours Sincerely,

A handwritten signature in black ink, appearing to read 'K. Lawrie', written in a cursive style.

Kirsten Lawrie

Senior Charge Nurse
Hemodialysis Unit

Included Documents:

Patient Information and Consent V4
Opt in/Opt out slip V1

Appendix 16: Staff Introductory Letter

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMF/CE device),
Staff Introductory Letter V3 date [24/10/23]



Dear

Direct Patient Care in the Haemodialysis Unit

I am writing to inform you of a research study which will be taking place within the haemodialysis unit in which you work, and would like to invite you to consider participating in this project.

The purpose of the study is to explore the direct patient care which occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The study will explore what happens in the Unit for staff and for patients.

The research will particularly focus upon these everyday caring activities and establish what direct care is within this setting and seek to understand what patients and staff think about direct care within haemodialysis. Information will be collected through observing what occurs, photographs and also some interviews.

Within the next few weeks, Alison Wood, the chief investigator for the project will be within the haemodialysis unit. She is a member of staff within the unit, and a trained nurse. The research project is part of a PhD at the School of Health In Social Science, at the University of Edinburgh.

If you or your family have any queries about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131 242-1201, or direct questions to her directly when you see her in the unit.

Yours Sincerely,

Kirsten Lawrie
Senior Charge Nurse

Staff Introductory Letter V3

Appendix 17: Patient Participant Information and Consent form- Observations and Photographs

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device)
Patient Information and Consent V4, date [24/10/13]



Participant Information Sheet and Consent Form

Direct Patient Care in the Haemodialysis Unit

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The research project will begin in November 2013 for approximately nine months and will be carried out by Alison Wood, a trained nurse in the team within the haemodialysis unit, who is conducting the project as part of a PhD.

What is the purpose of the study?

The purpose of the study is to explore the direct patient care that occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The study will explore what happens in the unit for staff and for patients. The research will focus particularly upon these everyday caring activities and establish what direct care is within this setting and seek to understand what patients and staff think about direct care within haemodialysis. Information will be collected through observing what occurs, photographs and also some interviews.

Why have I been asked to take part?

Everyone who attends for haemodialysis treatment is welcome to take part. You have been asked to take part as you regularly attend the haemodialysis unit for treatment.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights. If you decide not to take part, the research may still be carried out when you are in the haemodialysis unit but you will not be observed or used within the study.

What will happen if I take part?

The study is comprised of 3 aspects- observations, photographs and interviews, and you can participate in any or all of these aspects to the study.

The research involves the researcher watching what happens, taking notes on what is seen and asking questions about what is seen. Photographs will also be taken to show what is seen by the researcher and what occurs within the unit.

The main part of the study is the observations within the haemodialysis unit. If you choose to take part in the observations, Alison will remain within the haemodialysis unit for the duration of your treatment and observe what goes on whilst you receive haemodialysis. You may also be asked some questions as part of the observations. Your haemodialysis treatment will be unaffected by the presence of the researcher.

Photographs of patients and staff in the unit of different 'direct care' situations will also be taken by the researcher. This should not affect your treatment, and if you do not want to participate in the photographs, you can still participate in the observations.

The photographs will be altered to attempt and conceal identity, but confidentiality through photographs is not guaranteed. The photographs aim to show what direct care looks like in the haemodialysis unit, and you would be free to withdraw from the photograph aspect of the study, as with the other aspects, at any time.

A small number of participants will be asked to participate in an interview with Alison to discuss your perceptions and experiences of direct patient care as a haemodialysis patient. These interviews will last approximately one hour and will be audio recorded. If you participate in the interviews then you may choose for this to happen out with your treatment, but this is your choice and can happen when you are on haemodialysis.

What are the possible benefits of taking part?

There is not a direct benefit from taking part in this study. However the results of the research study may benefit the future care of haemodialysis patients.

What are the possible disadvantages and risks of taking part?

It is not thought that there are disadvantages to taking part in the study. The observations and photographs will be carried out during your haemodialysis treatment so will not have an impact on the quality of your haemodialysis treatment.

The entire study will take approximately nine months, so you may be observed a few different times within this period if you decide to participate. Observation sessions will last for the duration of a haemodialysis shift, so approximately 5 hours. Photographs will be taken whilst you are in the haemodialysis unit under the care of the nurses and healthcare support workers and will be minimally invasive to your treatment. The interviews will take approximately one hour.

Your haemodialysis treatment will be unaltered by the study and will not be affected or changed as part of the research.

Whilst the researcher is a trained haemodialysis nurse, she is also a registered nurse. As part of this, she has responsibilities and is duty bound to follow up or intervene in care should any untoward incident or emergency situation arise during the research

study. The researcher has a duty of care to protect patients and that will not change during the course of the study and will be acted upon.

What if there is a problem?

If you have a concern about any aspect of this study please contact Alison Wood who will do her best to answer your questions.

In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against NHS Lothian but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What happens when the study is finished?

At the end of the research you will be informed by Alison Wood that there will be no more observations, photographs or interviews and the project is over.

Will my taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Study researchers will need access to your medical records to carry out this research.

All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. You can view any information collected from you at any time on request.

With your consent we will inform your GP that you are taking part.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access your medical records and data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

All the observation notes and interview data will be anonymised so that you are not identifiable. Attempts to conceal your identity in the photographs will occur but is not guaranteed as you may still be able to be identified in the photograph despite this alteration to the images.

All data will be stored until the end of the project and then destroyed in accordance with the University of Edinburgh Data protection policy.

If during the study things change, and you are unable to consent to your continued participation in the study, then consent will be sought from a relative or guardian regarding your continued participation. All data generated before this will be kept

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and used, but if your relative does not provide consent on your behalf you will be withdrawn from further participation in the study.

What will happen to the results of the study?

The study will be written up as part of a PhD, with planned published papers and conference presentations. You will not be identifiable in any published results by name. If you choose to participate in the photographs, attempts will be made to hide your identity but cannot be guaranteed. The information from the observations and interviews will be kept anonymous and you will not be identifiable from the information.

Once the research is completed, a summary will be available to all participants if requested.

Who is organising the research and why?

This study is being organised by Alison Wood as part of a PhD with the support of Dr Jennifer Tocher and Dr Sheila Rodgers. The study is funded by the University of Edinburgh.

Who has reviewed the study?

The study proposal has been reviewed by Dr Jennifer Tocher and Dr Sheila Rodgers. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from Scotland A REC. NHS management approval has also been obtained.

If you have any further questions about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131) 242-1201

If you would like to discuss this study with someone independent of the study please contact by email:

Pam Smith, Head of Nursing Studies
pam.smith@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team
2nd Floor
Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708
complaints.team@nhslothian.scot.nhs.uk.

Thank you for taking the time to read this information sheet.

CONSENT FORM- OBSERVATIONS

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood

PhD Student, Nursing Studies, The University of Edinburgh

a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that *relevant sections of my medical notes and* data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that anonymised extracts from the observation notes may be used for research purposes or published and give permission for this to occur. ☐
5. I agree to my General Practitioner being informed of my participation in this study. ☐
6. I agree to take part in the observations as part of the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

CONSENT FORM- PHOTOGRAPHS

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood

PhD Student, Nursing Studies, The University of Edinburgh

a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation for the photographs is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I consent to the recording being shown to appropriate professional staff and used in educational publications, journals and used in any form or medium- including all forms of electronic publication or distribution anywhere in the world. ☐
4. I understand that the photographs may be used in conjunction with other photographs taken as part of the study. ☐
5. I understand that efforts will be made to conceal my identity, but full confidentiality is not guaranteed. ☐
6. I agree to take part in the photographs as part of the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Appendix 18: AWI Participant Information and Consent form- Observations and Photographs

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Welfare Guardian/Relative Information and Consent V4
date [24/10/13]



Participant Information Sheet and Consent Form Nearest Relative/Guardian or Welfare Attorney

Direct Patient Care in the Haemodialysis Unit

The person you care for is being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish your relative to take part.

The research project will begin in November 2013 for approximately nine months and will be carried out by Alison Wood, a trained nurse within the haemodialysis unit, who is conducting the project as part of a PhD.

What is the purpose of the study?

The purpose of the study is to explore the direct patient care that occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The study will explore what happens in the unit for staff and for patients. The research will focus particularly upon these everyday caring activities and establish what direct care is within this setting and seek to understand what patients and staff think about direct care within haemodialysis. Information will be collected through observing what occurs, photographs and also some interviews

Why has your relative been asked to take part?

Your relative has been asked to take part as they regularly attend the haemodialysis unit and receive treatment. Every patient who attends the unit for treatment on a regular basis is able to take part in the study.

However, they currently lack the capacity to make an informed decision about whether they can take place in a research study. We are therefore asking you as their nearest relative, welfare attorney or guardian if you will give consent on their behalf to join this study. This is permissible under the Adults with Incapacity (Scotland) Act 2000.

Does your relative have to take part?

No, it is up to you to decide whether or not your relative is to take part. If you do decide they can take part you will be asked to sign a consent form. If you decide your relative can take part and provide consent, you are still free to withdraw your relative at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your or their legal rights or treatment. If you decide your relative will not to take part, the research may still be carried out

Direct Patient Care in the Haemodialysis Unit
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Welfare Guardian/Relative Information and Consent V4
date [24/1013]



when your relative is in the haemodialysis unit but they will not be observed or used within the study.

What will happen if your relative does take part?

The study is comprised of 3 aspects- observations, photographs and interviews. The entire research project involves the researcher watching what happens, taking notes on what is seen and asking questions about what is seen. Photographs will also be taken to show what is seen by the researcher and what occurs within the unit.

The main part of the study is the observations within the haemodialysis unit and this is the aspect of which we are asking your relative to be part. If you choose for them to take part in the observations, Alison will remain within the haemodialysis unit for the duration of a haemodialysis treatment shift and observe what goes on whilst your relative is cared for on haemodialysis. Their treatment will be unaffected by the presence of the researcher.

Photographs and audio-recorded interviews will also be carried out as part of the study, however we are not asking for your relative's participation in these aspects as they may be distressing for your relative. Their involvement within the observation part of the study will allow for the haemodialysis unit to be looked at as a whole, rather than focusing on specific patient groups and their specific needs and the care they receive.

What are the possible benefits of taking part?

There is not a direct benefit from taking part in this study. However the results of the research study may benefit the future care of haemodialysis patients, especially for patients who are not as able to voice their direct care needs.

What are the possible disadvantages and risks of taking part?

It is not thought that there are disadvantages to taking part in the study. The observations and will be carried out whilst your relative is receiving haemodialysis treatment and will not affect the quality of the haemodialysis treatment

The entire study will take approximately 9 months, so your relative may be observed a few different times within this period if you decide they can participate in the study. Observation sessions will last for the duration of a haemodialysis shift, so approximately 5 hours. If your relative appears to be distressed by the presence of the researcher then the observation session will stop.

Whilst the researcher is a trained haemodialysis nurse, she is also a registered nurse. As part of this, she has responsibilities and is duty bound to follow up or intervene in care should any untoward incident or emergency situation arise during the research study. The researcher has a duty of care to protect patients and that will not change during the course of the study and will be acted upon.

Direct Patient Care in the Haemodialysis Unit
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date [24/1013]



What if there is a problem?

If you have a concern about any aspect of this study please contact Alison Wood who will do their best to answer your questions.

In the unlikely event that something goes wrong and your relative is harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against NHS Lothian but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What happens when the study is finished?

At the end of the research you will be contacted by Alison Wood to inform you that the project is over and that there will be no more observations.

Will my relative taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Study researchers will need access to your relative's medical records to carry out this research.

All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. You can view any information collected from you relative at any time on request. With your consent we will inform your relatives GP that they are taking part.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

All the observation notes and interview data will be anonymised so that your relative is not identifiable. All data will be stored until the end of the project and then destroyed in accordance with the University of Edinburgh Data protection policy.

What will happen to the results of the study?

The study will be written up as part of a PhD, with planned published papers and conference presentations. Your relative will not be identifiable in any published results by name. The information from the observations will be kept anonymous and your relative will not be identifiable from the information.

Once the research is completed, a summary will be available to all participants and relatives if requested.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Welfare Guardian/Relative Information and Consent V4
date [24/1013]



Who is organising the research and why?

This study is being organised by Alison Wood as part of a PhD with the support of Dr Jennifer Tocher and Dr Sheila Rodgers. The study is funded by the University of Edinburgh.

Who has reviewed the study?

The study proposal has been reviewed by Dr Jennifer Tocher and Dr Sheila Rodgers. All research in the NHS is looked at by an independent group of people called a Research Ethics Committee. A favourable ethical opinion has been obtained from Scotland A REC. NHS management approval has also been obtained.

If you have any further questions about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131) 242-1201

If you would like to discuss this study with someone independent of the study please contact by email:

Pam Smith, Head of Nursing Studies

pam.smith@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team

2nd Floor

Waverley Gate

2 - 4 Waterloo Place

Edinburgh

EH1 3EG

Tel: 0131 465 5708

complaints.team@nhslothian.scot.nhs.uk.

Thank you for taking the time to read this information sheet.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Welfare Guardian/Relative Information and Consent V4
date [24/1013]



CONSENT FORM- OBSERVATIONS

Nearest Relative/Guardian or Welfare Attorney

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood
PhD Student, Nursing Studies, The University of Edinburgh
a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my relative's participation is voluntary and that I am free to withdraw my relative at any time, without giving any reason and without my relative's medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my relatives taking part in this research. I give permission for these individuals to have access to my relative's records. ☐
4. I understand that anonymised extracts from the observation notes may be used for research purposes or published and give permission for this to occur. ☐
5. I agree to my relative's General Practitioner being informed of their participation in this study. ☐
6. I agree for my relative taking part in the observations as part of the above study. ☐

I confirm that I am the nearest relative for _____ and that no other nearest relative or welfare attorney or guardian exists.

Relationship to patient _____

I confirm that I am the Welfare Attorney or Guardian for _____

Name of relative/welfare guardian	Date	Signature

Name of Person taking consent	Date	Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Appendix 19: Staff Participant Information and Consent form- Observations and Photographs

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Information and Consent V4 date [24/10/13]



Participant Information Sheet and Consent Form

Direct Patient Care in the Haemodialysis Unit

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The research project will begin in November 2013 for approximately nine months and will be carried out by Alison Wood, a trained nurse in the team within the haemodialysis unit, who is conducting the project as part of a PhD.

What is the purpose of the study?

The purpose of the study is to explore the direct patient care that occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The study will explore what happens in the unit for staff and for patients. The research will focus particularly upon these everyday caring activities and establish what direct care is within this setting and seek to understand what patients and staff think about direct care within haemodialysis. Information will be collected through observing what occurs, photographs and also some interviews.

Why have I been asked to take part?

You have been asked to take part as you are a staff member within the haemodialysis unit who works in this area regularly.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your legal rights. If you decide not to take part, the research may still be carried out when you are in the haemodialysis unit but you will not be observed or used within the study and will not affect your role within the unit.

What will happen if I take part?

The study is comprised of 3 aspects- observations, photographs and interviews, and you are being asked to participate in all of these aspects to the study.

The research involves the researcher watching what happens, taking notes on what is seen and asking questions about what is seen. Photographs will also be taken to show what is seen by the researcher and what occurs within the unit.

Direct Patient Care in the Haemodialysis Unit
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The main part of the study is the observations within the haemodialysis unit. If you choose to take part in the observations, Alison will remain within the haemodialysis unit for the duration of a haemodialysis treatment shift and observe what goes on whilst you care for patients on haemodialysis. You may also be asked some questions as part of the observation sessions. Your work will be unaffected by the presence of the researcher.

Photographs of patients and staff in the unit of different 'direct care' situations will also be taken by the researcher.

The photographs will be altered to try and conceal identity, but confidentiality through photographs is not guaranteed. The photographs aim to show what direct care looks like in the haemodialysis unit, and you would be free to withdraw from the photograph aspect of the study as the other aspects at any time.

A small number of participants will be asked to participate in an interview with Alison to discuss your perceptions and experiences of direct patient care as a haemodialysis staff member. These interviews will last approximately one hour and will audio recorded. If you participate in the interviews, these will occur at a time of your choosing in a clinic room within the haemodialysis unit. These interviews will be audio recorded.

What are the possible benefits of taking part?

There is not a direct benefit from taking part in this study. However the results of the research study may benefit the future care of haemodialysis patients.

What are the possible disadvantages and risks of taking part?

It is not thought that there are disadvantages to taking part in the study. The observations and photographs will be carried out during your working day so will not have an impact on your work.

The entire study will take approximately 9 months, so you may be observed a few different times within this period if you decide to participate. Observation sessions will last for the duration of a haemodialysis shift, so approximately 5 hours. Photographs will be taken whilst you are working in the haemodialysis unit. The interviews will take approximately one hour.

Whilst the researcher is a trained haemodialysis nurse, she is also a registered nurse. As part of this, she has responsibilities and is duty bound to follow up or intervene in care should any untoward incident or emergency situation arise during the research study. The researcher has a duty of care to protect patients and that will not change during the course of the study and will be acted upon.

What if there is a problem?

If you have a concern about any aspect of this study please contact Alison Wood who will do their best to answer your questions.

In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against NHS Lothian but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What happens when the study is finished?

At the end of the research you will be informed by Alison Wood that there will be no more observations, photographs or interviews and the project is over.

Will my taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage.

All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. You can view any information collected from you at any time on request.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

All the observation notes and interview data will be anonymised so that you are not identifiable. Attempts to conceal your identity in the photographs will occur but is not guaranteed as you may still be able to be identified in the photograph despite this alteration to the photograph.

All data will be stored until the end of the project and then destroyed in accordance with the University of Edinburgh Data protection policy.

What will happen to the results of the study?

The study will be written up as part of a PhD, with planned published papers and conference presentations. You will not be identifiable in any published results by name. If you choose to participate in the photographs, attempts will be made to hide your identity but cannot be guaranteed. The information from the observations and interviews will be kept anonymous and you will not be identifiable from the information.

Once the research is completed, a summary will be available to all participants if requested.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Information and Consent V4 date [24/10/13]



Who is organising the research and why?

This study is being organised by Alison Wood as part of a PhD with the support of Dr Jennifer Tocher and Dr Sheila Rodgers. The study is funded by *the University of Edinburgh*.

Who has reviewed the study?

The study proposal has been reviewed by *Dr Jennifer Tocher and Dr Sheila Rodgers*. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from *Scotland A REC*. NHS management approval has also been obtained.

If you have any further questions about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131) 242-1201

If you would like to discuss this study with someone independent of the study please contact by email:

Pam Smith, Head of Nursing Studies
pam.smith@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team
2nd Floor
Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708
complaints.team@nhslothian.scot.nhs.uk.

Thank you for taking the time to read this information sheet.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Information and Consent V4 date [24/10/13]



CONSENT FORM- OBSERVATIONS

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood

PhD Student, Nursing Studies, The University of Edinburgh

a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to data collected involving my participation. ☐
4. I understand that anonymised extracts from the observation notes may be used for research purposes or published and give permission for this to occur. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Information and Consent V4 date [24/10/13]



CONSENT FORM- PHOTOGRAPHS

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood

PhD Student, Nursing Studies, The University of Edinburgh

a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I consent to the recording being shown to appropriate professional staff and used in educational publications, journals and used in any form or medium- including all forms of electronic publication or distribution anywhere in the world. ☐
4. I understand that the photographs may be used in conjunction with other photographs taken as part of the study. ☐
5. I understand that efforts will be made to conceal my identity, but full confidentiality is not guaranteed. ☐
6. I agree to take part in the photographs as part of the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Appendix 20: Patient Participant Information and Consent form- Interviews

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Patient Interview Information and Consent V4, date [24/10/13]



Participant Information Sheet and Consent Form

Direct Patient Care in the Haemodialysis Unit Interviews

You are being invited to take part in the interview part of a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The research project will begin in November 2013 for approximately nine months and will be carried out by Alison Wood, a trained nurse within the haemodialysis unit, who is conducting the project as part of a PhD.

What is the purpose of the study?

The purpose of the study is to explore the direct patient care that occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The research will focus particularly upon these everyday caring activities and establish what direct care is within this setting. Information will be collected through observing what occurs, photographs and also some interviews.

The interviews will allow more information to be gained about patient and staff experiences and views about direct patient care within this setting.

Why have I been asked to take part?

You have been asked to take part as you regularly attend the haemodialysis unit for treatment and have consented for the first two aspects of the study.

This interview part of the study aims for a wide variety of participants of different ages, both males and females and also people who have been on haemodialysis for both a long and short time. This is called purposive sampling to try and represent all the patients in the haemodialysis unit.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect the healthcare that you receive, or your legal rights.

What will happen if I take part?

You will be invited to participate in an interview with Alison to discuss your perceptions and experiences of direct patient care as a haemodialysis patient. These

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Patient Interview Information and Consent V4, date [24/10/13]



interviews will last approximately one hour and will be audio recorded. If you participate in the interviews then you may choose for this to happen out with your treatment, but this is your choice and can happen when you are on haemodialysis.

What are the possible benefits of taking part?

There is not a direct benefit from taking part in this study. However the results of the research study may benefit the future care of haemodialysis patients.

What are the possible disadvantages and risks of taking part?

It is not thought that there are disadvantages to taking part in the study; however you will require to give approximately 1 hour of your time to be interviewed. If this is carried out during your time in the haemodialysis unit, it will not have an impact on the quality of your treatment. If you choose to participate in the interview but would like this to happen before or after your haemodialysis treatment, or on a non-haemodialysis day, then this will take up some of your time when you would not normally be in the haemodialysis unit. Every effort will be made to conduct the interview at a time at your convenience within one of the clinic rooms in the out-patient haemodialysis area. Your haemodialysis treatment will be unaltered by the study and will not be affected or changed as part of the research.

Whilst the researcher is a trained haemodialysis nurse, she is also a registered nurse. As part of this, she has responsibilities and is duty bound to follow up or intervene in care should any untoward incident or emergency situation arise during the research study. The researcher has a duty of care to protect patients and that will not change during the course of the study and will be acted upon.

What if there is a problem?

If you have a concern about any aspect of this study please contact Alison Wood who will do her best to answer your questions.

In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against NHS Lothian but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What happens when the study is finished?

At the end of the research you will be informed by Alison Wood that there will be no more observations, photographs or interviews and the project is over.

The interview part of the research project will last approximately 1 hour.

Will my taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Study researchers will need access to your medical records to carry out this research.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Patient Interview Information and Consent V4, date [24/10/13]



All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. You can view any information collected from you at any time on request. With your consent we will inform your GP that you are taking part.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access your medical records and data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

All the interview data will be anonymised so that you are not identifiable. Once the interview has been conducted the audio recording will be transcribed and it will then be looked at to find themes from the interview. You may be asked to look at the themes which have come from your interview as a way of checking the results from the interview.

All data will be stored until the end of the project and then destroyed in accordance with the University of Edinburgh Data protection policy.

What will happen to the results of the study?

The study will be written up as part of a PhD, with planned published papers and conference presentations. You will not be identifiable in any published results by name.. The information from the interviews will be kept anonymous and you will not be identifiable from the information.

Once the research is completed, a summary will be available to all participants if requested.

Who is organising the research and why?

This study is being organised by Alison Wood as part of a PhD with the support of Dr Jennifer Tocher and Dr Sheila Rodgers. The study is funded by *the University of Edinburgh*.

Who has reviewed the study?

The study proposal has been reviewed by *Dr Jennifer Tocher and Dr Sheila Rodgers*. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from *Scotland A REC*. NHS management approval has also been obtained.

If you have any further questions about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131) 242-1201

If you would like to discuss this study with someone independent of the study please contact by email:

Perceptions and Experiences of Direct Patient Care

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Patient Interview Information and Consent V4, date [24/10/13]



THE UNIVERSITY
of EDINBURGH

Pam Smith, Head of Nursing Studies, pam.smith@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team
2nd Floor
Waverley Gate
2 - 4 Waterloo Place
Edinburgh
EH1 3EG
Tel: 0131 465 5708
complaints.team@nhslothian.scot.nhs.uk.

Thank you for taking the time to read this information sheet.

CONSENT FORM-INTERVIEWS

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood

PhD Student, Nursing Studies, The University of Edinburgh

a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that if I do take part the interviews will be audio recorded. ☐
5. I understand that anonymised extracts from the interviews may be used for research purposes or published and give permission for this to occur. ☐
7. I agree to take part in the interviews as part of the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Appendix 21: Staff Participant Information and Consent form- Interviews

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Interview Information and Consent V4 date [24/10/13]



Participant Information Sheet and Consent Form

Direct Patient Care in the Haemodialysis Unit Interviews

You are being invited to take part in the interview part of a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Talk to others about the study if you wish. Contact us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The research project will begin in November 2013 for approximately nine months and will be carried out by Alison Wood, a trained nurse in the team within the haemodialysis unit, who is conducting the project as part of a PhD.

What is the purpose of the study?

The purpose of the study is to explore the direct patient care that occurs within the haemodialysis setting, specifically between nurses, healthcare support workers and haemodialysis patients. The research will focus particularly upon these everyday caring activities and establish what direct care is within this setting. Information will be collected through observing what occurs, photographs and also some interviews.

The interviews will allow more information to be gained about patient and staff experiences and views about direct patient care within this setting.

Why have I been asked to take part?

You have been asked to take part as you are a regular staff member in the unit and have consented for the first two aspects of the study.

This interview part of the study aims for a wide variety of participants of different ages, both males and females and also people who have worked in the unit for different lengths of time and in different roles. This is called purposive sampling to try and represent all the staff groups in the haemodialysis unit.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Deciding not to take part or withdrawing from the study will not affect your legal rights.

Direct Patient Care in the Haemodialysis Unit
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Staff Interview Information and Consent V4 date [24/10/13]



What will happen if I take part?

You will be invited to participate in an interview with Alison to discuss your perceptions and experiences of direct patient care as a haemodialysis staff member. These interviews will last approximately one hour and will be audio recorded.

What are the possible benefits of taking part?

There is not a direct benefit from taking part in this study. However the results of the research study may benefit the future care of haemodialysis patients.

What are the possible disadvantages and risks of taking part?

It is not thought that there are disadvantages to taking part in the study; however you will require to give approximately 1 hour of your time to be interviewed. Participating in the interview will take up some of your time when you would not normally be in the haemodialysis unit. Every effort will be made to conduct the interview at a time at your convenience within one of the clinic rooms in the out-patient haemodialysis area.

Whilst the researcher is a trained haemodialysis nurse, she is also a registered nurse. As part of this, she has responsibilities and is duty bound to follow up or intervene in care should any untoward incident or emergency situation arise during the research study. The researcher has a duty of care to protect patients and that will not change during the course of the study and will be acted upon.

What if there is a problem?

If you have a concern about any aspect of this study please contact Alison Wood who will do her best to answer your questions.

In the unlikely event that something goes wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against NHS Lothian but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

What happens when the study is finished?

At the end of the research you will be informed by Alison Wood that there will be no more observations, photographs or interviews and the project is over.

The interview part of the research project will last approximately 1 hour.

Will my taking part in the study be kept confidential?

All the information we collect during the course of the research will be kept confidential and there are strict laws which safeguard your privacy at every stage. Study researchers will need access to your medical records to carry out this research.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Interview Information and Consent V4 date [24/10/13]



All information will be stored on password protected computers or in locked drawers at the University of Edinburgh. You can view any information collected from you at any time on request.

To ensure that the study is being run correctly, we will ask your consent for responsible representatives from the Sponsor and NHS Institution to access your medical records and data collected during the study, where it is relevant to you taking part in this research. The Sponsor is responsible for overall management of the study and providing insurance and indemnity.

All the interview data will be anonymised so that you are not identifiable. Once the interview has been conducted the audio recording will be transcribed and it will then be looked at to find themes from the interview. You may be asked to look at the themes which have come from your interview as a way of checking the results from the interview.

All data will be stored until the end of the project and then destroyed in accordance with the University of Edinburgh Data protection policy.

What will happen to the results of the study?

The study will be written up as part of a PhD, with planned published papers and conference presentations. You will not be identifiable in any published results by name. The information from the interviews will be kept anonymous and you will not be identifiable from the information.

Once the research is completed, a summary will be available to all participants if requested.

A presentation for staff members will also occur to inform of the results of the project.

Who is organising the research and why?

This study is being organised by Alison Wood as part of a PhD with the support of Dr Jennifer Tocher and Dr Sheila Rodgers. The study is funded by the University of Edinburgh.

Who has reviewed the study?

The study proposal has been reviewed by *Dr Jennifer Tocher and Dr Sheila Rodgers*. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. A favourable ethical opinion has been obtained from *Scotland A REC*. NHS management approval has also been obtained.

If you have any further questions about the study please contact Alison Wood by email: a.f.wood@sms.ed.ac.uk or at the haemodialysis unit (0131) 242-1201

If you would like to discuss this study with someone independent of the study please contact by email:

Perceptions and Experiences of Direct Patient Care

Direct Patient Care in the Haemodialysis Unit
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Pam Smith, Head of Nursing Studies

pam.smith@ed.ac.uk

If you wish to make a complaint about the study please contact NHS Lothian:

NHS Lothian Complaints Team

2nd Floor

Waverley Gate

2 - 4 Waterloo Place

Edinburgh

EH1 3EG

Tel: 0131 465 5708

complaints.team@nhslothian.scot.nhs.uk

Thank you for taking the time to read this information sheet.

Direct Patient Care in the Haemodialysis Unit
PISCF (non-CTIMP/CE device),
Staff Interview Information and Consent V4 date [24/10/13]



CONSENT FORM-INTERVIEWS

Direct Patient Care in the Haemodialysis Unit

Participant ID:

Alison Wood

PhD Student, Nursing Studies, The University of Edinburgh

a.f.wood@sms.ed.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet (as specified in this document header) for the above study and have had the opportunity to consider the information and ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my legal rights being affected. ☐
3. I understand that data collected during the study may be looked at by individuals from the Sponsor, from the NHS organisation or other authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that if I do take part the interviews will be audio recorded. ☐
5. I understand that anonymised extracts from the interviews may be used for research purposes or published and give permission for this to occur. ☐
6. I agree to take part in the interviews as part of the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

1x original – into Site File; 1x copy – to Participant; 1x copy – into medical records

Appendix 22: Search Strategies

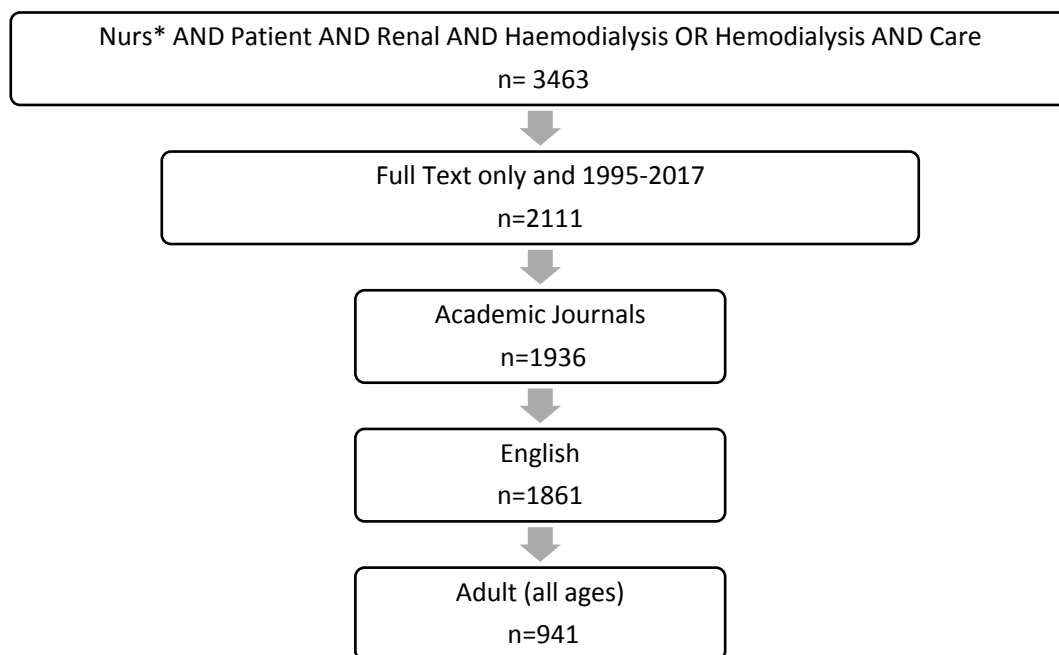


Figure 73: Search Strategy using CINAHL

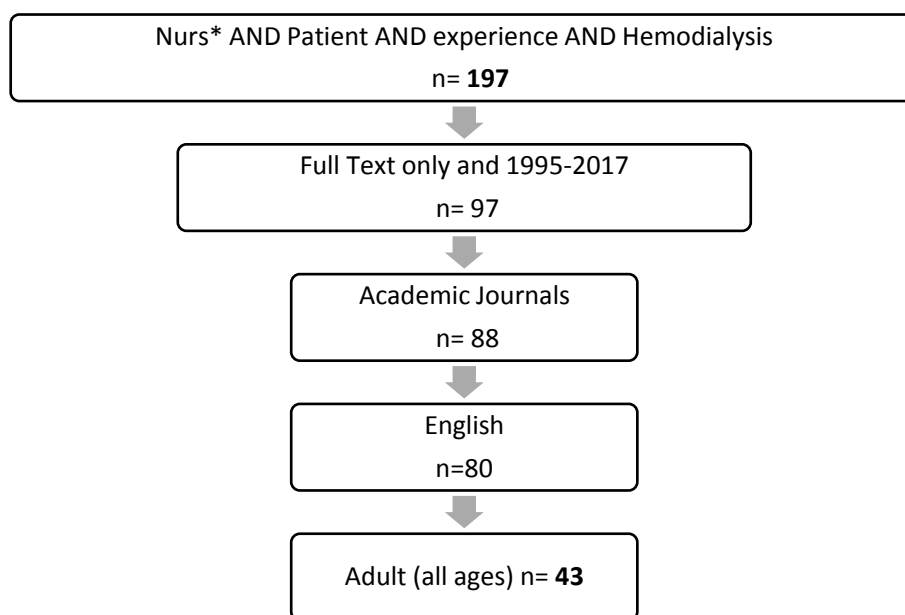


Figure 74: Search Strategy using CINAHL

Perceptions and Experiences of Direct Patient Care

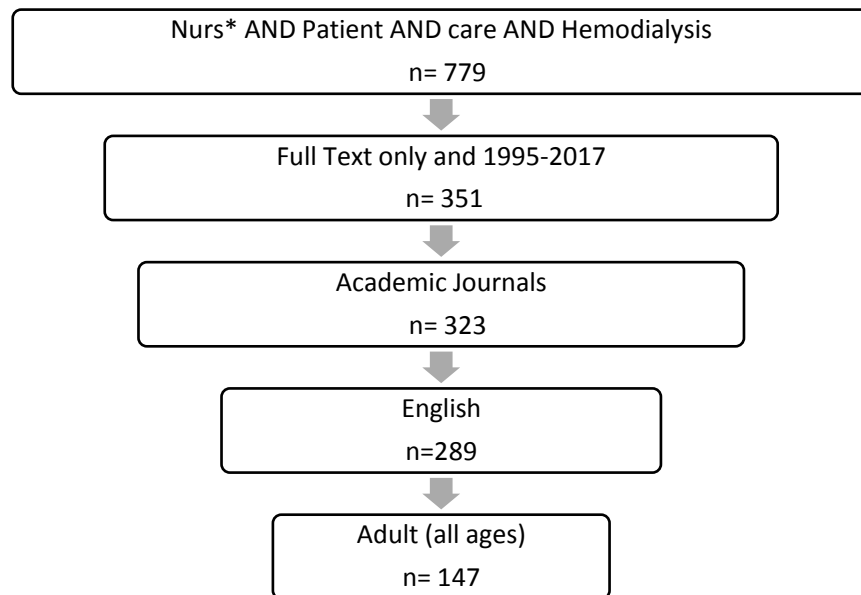


Figure 75: Search Strategy using CINAHL

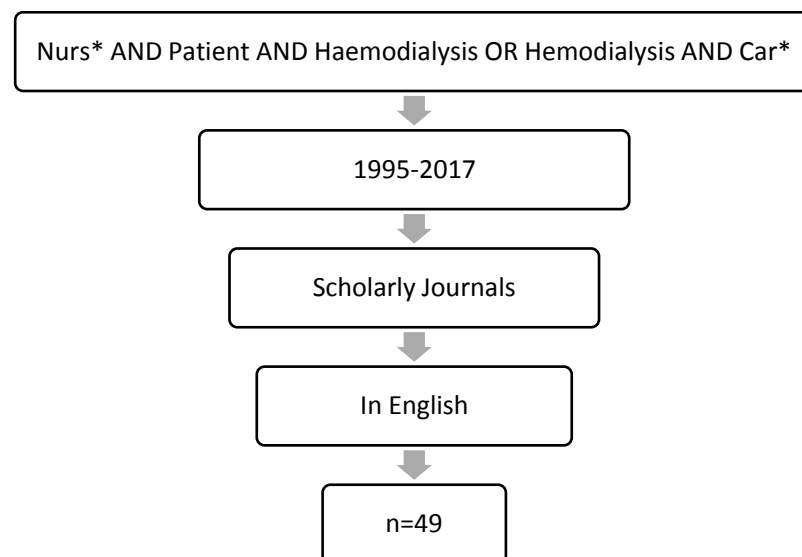


Figure 76: Search Strategy using Applied Social Sciences Index and Abstracts (ASSIA)

Perceptions and Experiences of Direct Patient Care

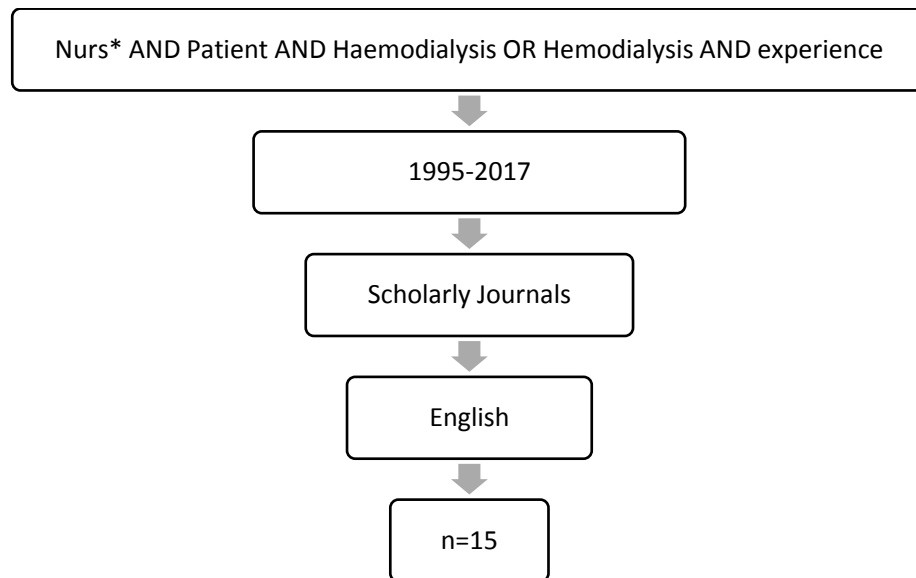


Figure 77: Search Strategy with keywords using Applied Social Sciences Index and Abstracts (ASSIA)

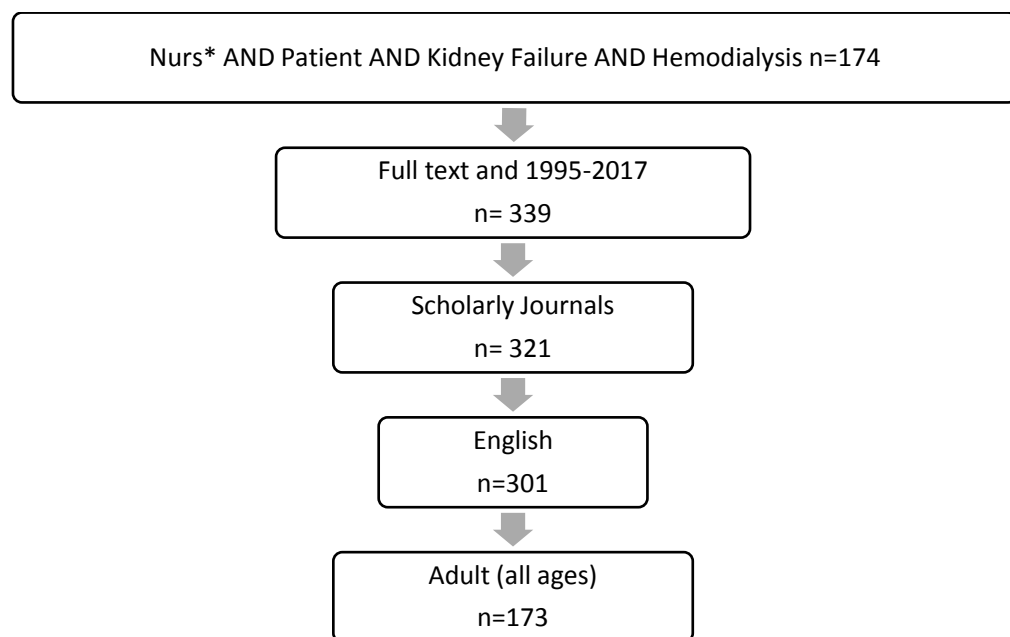


Figure 78: Search Strategy with Key words using CINAHL

Appendix 23: Data Collection Gantt chart

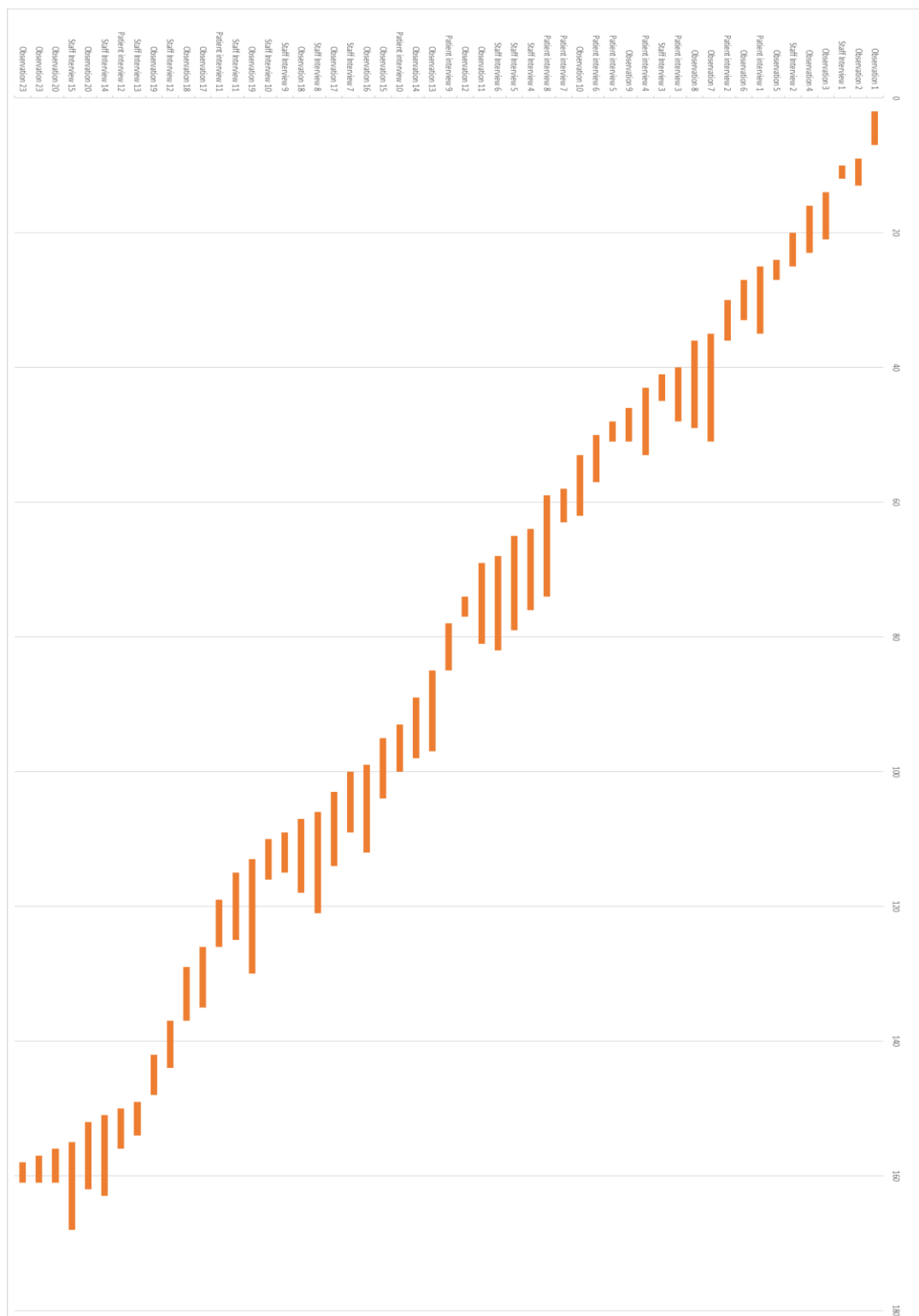


Figure 79: Gantt chart

Chart shows the data collected and length of initial analysis, including the overlap of both data collection and analysis.

Appendix 24: Order of Data Collection

Observation Session	Interview Number	Days since start	No of days for initial
Observation 1		0	5
Observation 2		3	4
	Staff Interview 1	4	2
Observation 3		13	7
Observation 4		15	7
	Staff Interview 2	16	5
Observation 5		24	3
	Patient interview 1	25	10
Observation 6		27	6
	Patient interview 2	30	6
Observation 7		35	16
Observation 8		36	13
	Patient interview 3	40	8
	Staff Interview 3	41	4
	Patient interview 4	43	10
Observation 9		46	5
	Patient interview 5	48	3
	Patient interview 6	50	7
Observation 10		53	9
	Patient interview 7	58	5
	Patient interview 8	59	15
	Staff Interview 4	64	12
	Staff Interview 5	65	14
	Staff Interview 6	68	14
Observation 11		69	12
Observation 12		74	3
	Patient interview 9	78	7
Observation 13		87	12
Observation 14		89	9
	Patient interview 10	93	7
Observation 15		95	9
Observation 16		99	13
	Staff Interview 7	100	9
Observation 17		103	11
	Staff Interview 8	106	15
Observation 18		119	11
	Staff Interview 9	120	6
	Staff Interview 10	130	6
Observation 19		131	17
	Staff Interview 11	140	10
	Patient interview 11	142	7
Observation 17		150	9
Observation 18		154	8
	Staff Interview 12	157	7
Observation 19		165	6
	Staff Interview 13	168	5
	Patient interview 12	175	6
	Staff Interview 14	176	12
Observation 20		195	10
	Staff Interview 15	196	13
Observation 21		197	5
Observation 22		198	4
Observation 23		199	4

Appendix 25: Section of Node Structure

The screenshot displays the NVivo 10 interface for managing qualitative data nodes. The top toolbar contains various editing and formatting tools. The search bar at the top indicates a search for 'Nodes'. The main panel, titled 'Nodes', shows a hierarchical tree structure of nodes. The 'DPC communication- verbal, banter' node is currently selected and highlighted in blue. The tree structure is as follows:

- ANYTHING ABOUT ME FROM INTERVIEWS
 - Asking me a question as a nurse or colleague not as researcher
 - community spirit comradery support with patients in the room or lack of!
 - CSW's specifically
 - dialysis going well or needing it to go well
- Direct Care- time together
 - having to deliver care to more than one...
- DPC
 - availability
 - DPC- 2 things at once, multitasking
 - not delivering DPC
 - language as a barrier
 - not listening or one sided care
 - visability
- DPC questions
- DPC communication- verbal, banter (highlighted)
- DPC psychosocial support
 - psychosocial support given, due to patient
- DPC safe
- DPC telling staff information
- DPC education or explanation
- DPC physical care dialysis treatment and fistula stuff
- DPC comfortable
- DPC when on dialysis having time with staff
- DPC time and attention from the staff to the patient
- DPC confidence and getting to know staff
- DPC- staff listening to patients
- environment
 - environment as a barrier to DPC
- History about renal failure and prehd
- Identity

Figure 80: Section of Final Node Structure from NVIVO 10